FACTORS INFLUENCING ENTRY TO RESIDENTIAL CARE AMONG OLDER PEOPLE

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Factors influencing entry to residential care among older people

Abstract

With the population increasing, and the occupancy and dependency levels of older people in residential care rising, it is essential to examine the factors surrounding admission. The reasons for an older person choosing to move to residential care in New Zealand are not well documented, and little evidence surrounds the process. Clearly there is interplay of many factors, such as risk mitigation by health professionals, co-morbid disease, and concerns of the family.

Objective: To seek out the significant factors and influences which persuade an older person to enter residential care, and the subsequent satisfaction.

Design: Longitudinal mixed methods design (N = 131), using interviews with older people who were referred by the Needs Assessment Services Co-ordination (NASC). Also interviewed were caregivers, NASC managers, and the Multi-disciplinary team. This research, called Older People Entering Residential Accommodation (OPERA) was a sub-study of the Assessment of Services Promoting Independence and Recovery in Elders (ASPIRE) trial (N=569). The data from ASPIRE was also available for use in the analysis. Face-to-face or telephone interviews were held with older people in three cities who needed substantial levels of support.

Findings: The most significant factors for increasing the likelihood of residential care entry were: to have the potential care-giving child living far away, and needing a lot of support with the higher level daily living tasks. Also significant was the older person being home alone for long periods. It was clearly shown that while the doctor had the most influence over the person's entry into residential care, the older person had the most influence with the decision to stay at home. The vast majority of the older people staying at home were happy with their decision to stay there, but unfortunately the vast majority of older people who entered residential care were unhappy with their decision to move there.

Conclusions: This study demonstrated who was at risk of residential care entry, who had the controlling influence, and the subsequent older person satisfaction. Also highlighted was the need for improved communication to the older person, with improved community support and more customer-focused residential care.

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Abbreviations

Abbreviation	Meaning
ACC	Accident Compensation Corporation
ADL	Activities of Daily Living
AIP	Ageing In Place
AIPI	Ageing In Place Initiative
ASPIRE	Assessment of Services Promoting Independence and Recovery in Elders
AT&R	Assessment, Treatment and Rehabilitation
CHESS	Changes in Health, End-stage disease and Signs and Symptoms
COSE	Co-ordinated Services to the Elderly
CPS	Cognitive Performance Scale
DHB	District Health Boards
FIRST	Flexible Integrated Rehabilitation Support Team
GP	General Practitioner
IADL	Instrumental Activities of Daily Living
MDS-HC	Minimum Data Set-Home Care
MDT	Multi-Disciplinary Teams
MMSE	Mini Mental State Examination
MoH	Ministry of Health
MSP	Ministry of Social Policy
NASC	Needs Assessment Service Co-ordination
OECD	Organisation for Economic Co-operation and Development
OPERA	Older People Entering Residential Accommodation
PAS	Positive Ageing Strategy
PIP	Promoting Independence Programme
PSR	Potential Support Ratio
RCT	Randomised Controlled Trial
WHO	World Health Organisation

Chapter 1

Introduction

And once set out, a word takes wings beyond recall
Quintus Horatius Flaccus (known as Horace) 65-8 BC

‘You can’t stay at home any longer and will now have to go to a rest home’ are words which most older people dread. The preferred option for older people is certainly that of maintaining independence in the family home (Hambly, 2003). As the person ages this is inextricably linked in most of their minds with rest homes, which are perceived to be the end point of care by the health professionals (Nolan et al., 1996) and the place of internment, demonstrated by one older man who said: *“I don’t want to be incarcerated in an old folks home”* (T.S.)[1]. On the other hand it is the salvation for some informal caregivers (Nolan & Dellasega, 2000); and the place of welcome social interaction for other older people (Mattimore et al., 1997).

Residential care is a term used in New Zealand for institutions providing full-time accommodation for older people. These offer varying levels of support such as ‘high level support’ which equates with rest homes, ‘very high level support’ equating with continuing care hospitals, and secure facilities for people with dementia. There are many reasons which can lead to an older person permanently entering residential care, but despite these some older people who need high or very high levels of support, can continue living in their own homes.

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[1] The initials used referring to the older people are pseudonyms

Medical advances in the last few decades, coupled with increased awareness of healthy lifestyles, have contributed to the burgeoning population of older people. While it has been predicted that older people constitute the fastest-growing segment of many populations (*World population prospects:*2006), studies have also demonstrated that the older population is healthier than ever before (Bonita, Beaglehole, & North, 1984; Feigin, Lawes, Bennett, & Anderson, 2003; Truelsen, Bonita, Duncan, Anderson, & Mee, 1998). However, the prediction is that, due to the rising disability among the younger cohorts that are beginning to approach old age, there will be a substantial increase in the incidence of residential care admissions among older people (Bhattacharya et al., 2004; Binstock, Cluff, & Von Mering, 1996; Lakdawalla et al., 2003).

The Health of Older People Strategy (Ministry of Health, 2002b) was a published guide for the District Health Boards to assist in the provision of services for older people. Central to this policy was the 'Ageing-In-Place' strategy which aimed to establish appropriate community services where both the Ministry of Health and the Ministry of Social Policy agreed to work together to ensure a workable programme was established. Both Ministries were interested in older people having a choice of where they lived and also having a real option of choosing to remain living in their own homes (ageing-in-place) (Ministry of Health, 2001a; *The New Zealand positive ageing strategy:*2001). There is strong evidence this is still a very topical issue, with rest home closures increasing (Chalmers, 2005) and a Ministry of Health spokesperson saying the Ministry of Health does not provide funding for 24-hour support in an individual's home (Andrew, 2005).

There has been little research published within New Zealand regarding where the highly dependent older person wishes to live permanently, or the factors which contribute to their permanent entry into residential care. Nor is it known within New Zealand who makes the final decision of where the older person lives (residential care or home), or the older person's satisfaction with that decision. It is desirable that the ability to exercise choice and maintain an element of control is exercised by the older person (Nolan et al., 1996). However, it has been found in Australia and elsewhere that the majority of residential care residents did not participate in their relocation (Nay, 1995; Nolan & Dellasega, 2000).

Little research was found addressing the impact of family dynamics on the autonomy of the older person who was still cognitively capable (Kapp, 1992). A sequential domination can be seen in the role of other family members, such as spouses, adult daughters, or daughters-in-law, making healthcare decisions for decisionally incapacitated older people. The erosion of the older person's autonomy, particularly in the home environment, may be gradual, and the nature of those mundane decisions may mask the loss of independence which occurs. On the other hand, there has been considerable research into the part of the family and health professionals, particularly in the USA and Europe, in the placement decision-making process. The largest threat to the older person's autonomy is the common practice of providing the information to the family prior to, or usually instead of, the older person (Kapp, 1992; Lichtenberg, MacNeill, Lysack, Bank, & Neufeld, 2003; Nay, 1995; Nolan et al., 1996; Sandberg, Lundh, & Nolan, 2001). Autonomy, which stands for respect for people and their free choice or self-determination, stems from the Greek etymological root of the words for 'self rule.' Justice Cardozo in a medical malpractice decision stated: "*Every human being of adult years and sound mind has a right to determine what shall be done with his own body*" (Kapp, 1992, p. 779).

Although the aspect of the older person's satisfaction with the eventual placement has not been researched fully, there have been articles regarding the satisfaction of the primary informal caregivers, usually a family member (Nolan & Dellasega, 2000). The families' perceptions about residential care for the older person were vastly different depending on the experiences of the family as a whole (Rodgers, 1997). One overriding perception was that residential care would be safer for the older person in the protected environment with ready access to nursing support, thus alleviating some of the family's responsibilities.

There have been numerous factors documented which precipitate entry to residential care including lack of support, dementia, physical impairments, and other co-morbid medical conditions (A. Bebbington, Brown, Darton, & Netten, 1995; Miller & Weissert, 2000). However the priorities differ within each report. Various predictors of residential care entry such as acute hospital admissions, sudden loss of spouse, or an acute medical illness have also been documented (Lee, Woo, & Mackenzie, 2002; Lundh, Sandberg, & Nolan, 2000; Morgan, Reed, & Palmer, 1997). This New Zealand study, 'Older People Entering Residential Accommodation' (OPERA) investigated who makes the decision about whether the older person needing high or very high levels of support lived in their own homes or in residential care. It also examined the older person's satisfaction with the outcome, and the factors which influenced that decision. By addressing these issues a more comprehensive understanding of who were the decision-makers, factors of residential care entry, and the subsequent older person's satisfaction can be obtained.

The recently completed research ASPIRE (Assessment of Services Promoting Independence and Recovery in Elders), by the Clinical Trials Research Unit at The University of Auckland, examined three 'ageing-in-place' initiatives for their effectiveness to prevent or delay entry into residential care. The ASPIRE trial was clearly not examining the process of entering residential care, which is crucial to fully understanding the concept of ageing-in-place. Therefore, OPERA has been developed as a sub-study, and is both informed by and informs the larger ASPIRE trial. The data collected from the ASPIRE trial were also available for collation with the OPERA data to enhance and triangulate information.

My perspectives come from a background as a health professional, working in the public and private health systems, and prior to commencing the study working for a Trust which owned retirement villages.

1.1: Research objectives

This research developed from the advent of the New Zealand Government's Ageing-in-place strategy, which encouraged older people to remain in their homes, as an option to residential care. With the burgeoning population of older people it seemed very relevant to understand the reasons why people enter residential care, and also who makes this decision.

It is envisaged that the results gained from this study will lead to a greater understanding of the processes involved in the older person's residence decision (either continuing to live at home or residential care), and the extent of their satisfaction. The results included potential modifiable factors that ensure older people who are at risk of entering residential care, and the key decision-makers, will be better informed. It is hoped that the resulting information will enable a greater number of older people to age-in-place.

The aim of the research from which the objectives were derived was therefore to provide a clear understanding of the risk factors for residential care entry, in order to prevent or delay admission, and ensure that the older person has a real choice of where they wish to live.

Objectives:

1. To identify key factors which lead to the older person entering residential care;
2. To identify key decision-makers when an older person enters residential care;
3. To determine whether the older person was satisfied with the decision regarding where they were to live.

OPERA (N=131), with its high proportion of qualitative input, was developed as a sub-study of ASPIRE (N=569) to collect information more conducive to mixed methods research. The data from both OPERA and ASPIRE were used in the subsequent analysis of the risk factors, and decision-makers in reference to residential care entry.

Chapter two reviews the more recent literature in three parts. Part one focuses primarily on how the world for the older people is changing and its progression to the year 2050. How these changes affect policies and services is followed by a historical description of the services. Part two focuses on the reasons why people enter residential care and which are the most commonly noted risk factors. The decision surrounding residential care entry and who makes that decision, and the older person's satisfaction with the residence decision is examined in Part three.

Chapter three gives an overview of the ASPIRE trial, its objectives, structure and an examination of the three 'Ageing-in Place' initiatives which the trial is examining. A review of the literature regarding mixed methods research and the other areas of research used in this study are seen in Chapter four, Methodological review. The methods used in OPERA are outlined in Chapter five, which describes in detail the process taken from commencement to conclusion of the analysis. There are two parts to Chapter six which describe the findings: part one gives text and narrative of the qualitative findings, and part two analyses the numbers to support the qualitative findings. The Discussion Chapter (Chapter seven) combines the two previous chapters and discusses their findings in comparison with the literature reviewed and current Government policy. Implications for policy and practice, recommendations for future research, conclusions and summary follow.

Chapter 2

A review of the literature:

> *And in the end, it is not the years in your life that counts; it is the life in your years* Abraham Lincoln (1809-1865)

The review of the literature in this Chapter seeks to provide an insight into why some older people relocate to residential care, who makes that decision, and finally if the older person is happy with the decision. Part 1 examines how the population is changing and what policies and support are accommodating these changes. The anticipated dramatic increase in the number of older people has created a need to identify causes, future projections and relevance to residential home usage amongst older people in New Zealand. Towards this end a review of the literature has been undertaken, in order to make comparisons and find information relevant to New Zealand older people. Part 2 seeks the factors which have influenced the decisions surrounding residential care entry, while Part 3 considers the choices available for the older person, and who is the major decision-maker. Also considered is the happiness of the older person, with the decision.

The quality of life and wellbeing of older people depends heavily on their capacity to manage opportunities and risks associated with change. As people age the prospect of change becomes less appealing (Herzog & Rodgers, 1981) (USA), which makes the New Zealand Government's initiative of Ageing-in-place (AIP) important. However, a more recent study examining age differences in coping resources between young old and older old people disputes that age makes a difference to the older persons' acceptance of change and therefore satisfaction. The study does add that there is a likelihood of more stress as people age (Hamarat et al., 2002) . A change of residence is stressful for any age group, hence the promotion of 'Ageing-in-Place' (AIP). In recent years, both academic and public interest in the ageing and the subsequent placement of a growing percentage of older people within residential care, has burgeoned.

2.1: The literature search

Articles reviewed were accumulated through computer searches of a number of medical, nursing, psychology and allied health databases, with most articles being found in the MEDLINE, CINAHL, AMED, PsycINFO, ERIC and Journals @Ovid full text databases. The University of Auckland's Philson, Tamaki and General Libraries were used for all manual searches, and online searches were undertaken using the Internet search engine Google (http://www.google.co.nz), by manually searching the Ministry of Health web page (http://www.moh.govt.nz) and the public libraries databases through http://www.library.huttcity.govt.nz. Key words in the literature search included 'aged', 'residential care', 'caregivers', 'decision-making', 'wishes', 'loneliness', 'control', 'admission', 'patient satisfaction', 'home' and 'communication'. Publications, reports and books by the Ministry of Health and Ministry of Social Development were used as resources. The libraries of the Victoria University of Wellington, and the Hutt District Health Board were utilised for manual searches of likely scientific journals and publications. Two primary inclusion criteria were adopted. Firstly, the article had to include 'aged', 'elderly', 'older people', 'over 65' (or like as in age) in its sample population. Secondly, the article had to refer to the older people who needed substantial levels of support, or long-term support, either at home, or within residential care.

2.2: Study definitions

It is beneficial to define the key words older people, ageing-in-place, assessment, support services and residential care in relation to their context within this paper. Words can have different interpretations and meanings in different settings.

Older people have been defined by the Oxford dictionary as advanced in age; far on in the natural period of existence. People's ageing is said to be a natural process or*:*

> *a multifaceted phenomenon that begins at birth, and follows varied timetables depending on whether one is tracing biological, cognitive or social parameters* (Binstock & George, 1990, p. 21).

The World Health Organisation (WHO) had difficulty defining a specific age as 'old' because 'old' is a social construction (*Active ageing: A policy framework*, 2002). It could however be described as a set of cultural beliefs about people that are becoming increasingly blurred with early retirement and unemployment (Bowling & Ebrahim, 2001) (USA). Old age does not start specifically at any particular age with the changes of age being varied and complex (Tinker, 1993) (UK). This study has taken the New Zealand retirement age of 65 as defining the older person. This is similar to the Americans who adopted Otto von Bismarck's German people's age of eligibility for the state pension as 65 years of age, even though in those days few people reached that age (Markson & Hollis-Sawyer, 2000) (USA).

Ageing-in-Place (AIP) is a concept developed by health and social policy ministers from Organisation for Economic Co-operation and Development (OECD) countries. This concept refers to older people who require supported living being able to continue to live in their own home or where this is not possible to enable them to live in a sheltered supportive environment which is as close to their community as possible (World Health Organization, n.d.). The concept of AIP does not necessarily mean that the older person must stay in the family home permanently. It can mean moving to a more suitable, perhaps smaller home nearer to facilities such as shops, while maintaining links with family. One of New Zealand's AIP strategies is to encourage new initiatives which support older people in their own homes. These include funding for increased levels of support services, rehabilitation, and 'case management', which all aim to enable people to stay within the community (Ministry of Health, 2001a;

New Zealand Positive Ageing Strategy Action Plan, 2004; *The New Zealand positive ageing strategy,* 2001).

Assessment is a key part of the decision process of any AIP initiative and residential care entry. It is used to determine older people's abilities, needs and where possible to develop a support package which meets those needs (*Assessment processes for older people*, 2003; Ministry of Health, 2005). Assessment teams funded by the District Health Boards (DHB) are either situated within acute public hospitals in the Assessment, Treatment and Rehabilitation Units (AT&R), or are separate entities within the communities. The multi-disciplinary teams (MDT) are composed of specialists in the medical, social and physical fields. The MDT ideally, along with the families and the older person, make decisions regarding the future living arrangements and support of the older person in light of their needs. The Needs Assessment Service Coordination managers (NASC) also funded by the DHBs, coordinate the support services, and if necessary placement in residential care when no other option is available (*Assessment processes for older people*, 2003).

Support services can be firstly formal, which are funded privately or by the DHB, Accident Compensation Corporation (ACC), or insurances. The second option is the informal support from family and friends. The Ministry of Health (MoH) has defined 'support' as assistance in home services. This includes personal support, household management, support such as respite care, environmental support such as equipment, home or vehicle modifications, and residential care (Fletcher & Lynn, 2002) (NZ).

Residential care is the term depicting 24-hour support in institutions for older people. This consists of three types:

(i) Continuing-care hospitals for people with very high support needs;

(ii) Rest homes for people with high support needs; and;

(iii) Secure facilities for people with dementia.

Residential care facilities within New Zealand are almost exclusively privately owned. The facilities include small owner-operated rest homes and/or hospitals, not-for-profit religious and welfare small or large multi-sited operations, and for-profit facilities which are usually large multi-sited organisations (Ashton, 2000) (NZ). The majority of the providers accept both Government subsidised and private paying residents.

Part 1: Changes and support for older people

2.3: Population changes; effects on policies, funding and services

The predicted population ageing will have significant implications for society and the economy as a whole. Supporting and ensuring that the needs and wellbeing of older people are met within our societies will be a challenge. The population worldwide is changing with the average age increasing and the number of older people growing rapidly. As well as the population ageing, the characteristics of the four generations born within the last 50 years have changed, from one of subservience and autocratic leadership, to totally ‘plugged-in’ citizens of the world fully conversant with the technological advances. The world population is in the process of a dramatic change, which is without parallel in the history of humanity. Leading the changes has been the doubling of the population in less than 40 years to reach six billion, with a 78 million person increase in just the five years from 1995 to 2000. The predictions for the world future are just as dramatic. By 2015, 98 percent of the population will be living in developing countries and by 2050 the number of older people in the world will exceed the younger (*Charting the progress of populations*, 2000; *World population ageing*, 2002; *World population prospects*, 2004).

While predictions for the future are usually extrapolations of the trends of the past, they are possible for shorter time periods but may lead to problems if extended over centuries (Stauffer, 2002) (Germany). The prediction for population ageing is pervasive, having a direct bearing on inter-generational and intragenerational solidarity upon which societies are built. It is also profound, with implications for all areas of human life, including the economy, labour markets, health, and family compositions (*World population ageing*, 2002). While it is evident that these significant major changes in the demographics had their origins in the past two centuries, they will now carry on well into the twenty-first century, presenting great opportunities as well as enormous challenges.

The ageing population worldwide has primarily been the result of the transition from high to low levels of fertility and mortality (Schulz, Leidl, & Konig, 2004) (Germany). It is generally agreed that the population is ageing. However, Stauffer (2002) in his article looking at German populations, argues that in most of the developed countries an increase of the immigration by half a percent of the population per year could substantially stop the increase in the median age (Stauffer, 2002). The fertility factor describes the decline in the under 15-year-old population and a definite slowing of the projected growth of people within working age (Wiener & Tilly, 2002; *World population ageing*, 2002) (USA). In the developed countries there has been a sustained decrease in total fertility since at least 1900, and worldwide low fertility rates have persisted since the 1970s, but peaking in the period of 1985-1990 (Kinsella & Velkoff, 2001) (USA) . Subsequent decline in fertility in most regions has decreased the growth of population to around 0.5 percent per year and this will progressively get substantially lower (*World population prospects*, 2004).

The decline in mortality, especially in the underdeveloped countries, is illustrated by the average world life expectancy at birth, which was 46 years during 1950-1955, but increased to 66 years 50 years later. The under developed countries had more dramatic life expectancy increases. Reducing some major causes of death such as tuberculosis in Eastern Europe, has produced declines in mortality overall. However, this is not so for males in Eastern Europe, who in recent years have had a dramatic decline in life expectancy of 7.3 years, possibly due to a combination of factors such as homicide, accidents, alcohol excesses, and poor diet. Elsewhere the HIV/AIDS epidemic in Africa has had devastating impacts on life expectancy by a reduction of more than 30 years (Kinsella & Velkoff, 2001; Lutz, Sanderson, & Scherbov, 2001) (USA). This epidemic is also having an effect on the older populations in countries such as the United States of America (USA). Three times as many people aged 60 and over died of AIDS as people under the age of 20 and this is increasing (Kinsella & Velkoff, 2001).

There is a significant difference in the life expectancy of males and females in the developed countries. The gap is likely to decrease if women increase their use of tobacco and alcohol, and their participation in the paid workforce. The smaller gender difference in the underdeveloped countries is likely to rise as the consumption of alcohol and tobacco increases more rapidly in males (Kinsella & Velkoff, 2001). Life expectancy from age 65 excludes the early-life mortality, and is more relevant. Over the past decade this rose 1.2 years over 18 years to reach 82.7 years in the USA, and from the age of 85, life expectancy rose by only four months. Future trends for increases in life expectancy will remain modest (Fries, 2003). Hand in hand with the modest increase in life expectancy is the decline of two percent in morbidity, due to many factors which could include a reduction in health risk, although this has not been conclusively proven (Freedman, Martin, & Schoeni, 2002; Fries, 2003).

The effects of the World War 2 Baby Boomer cohorts (born 1946 to 1960), common to many countries is another factor in the projected increase in the number of older people, particularly around the year 2010. This will reach significant proportions by 2030 especially within the group of the oldest old. These effects will be felt within and across national boundaries (Kinsella & Velkoff, 2001). Overall, the decline in the replacement of younger people and longevity of the older people both steer the proportions of young and old to what is now termed an ‘ageing population’.

How the generations are changing over time

Change is inevitable and each generation can be said to be distinct and different from the previous one, or the future one. Societies such as the USA have diametrically shifted from the days when the older person was thought unnecessary in an industrialised society and should be cast into an almshouse (Markson & Hollis-Sawyer, 2000).

In the early 1900s until the beginning of the 1950's, women were expected not to work outside the home. Women had large families and there was high infant mortality as well as one pregnancy in 10 resulting in maternal death. The youngest daughter in the family was expected to stay single to look after the parents, and few people lived to see the birth of their grandchildren (Markson & Hollis-Sawyer, 2000; Thorson, 2000). These examples provide a sharp contrast to today's generation, and point to markedly different expectations, life expectancy, mortality, educational attainment, and support for the older people (Markson & Hollis-Sawyer, 2000). Not only have the demographics of the population changed, but the attitudes of its people are also altering in many countries. This is demonstrated by the lifting of female suppression intellectually and physically, to one of encouraging female participation. In some cases females can now rise to senior positions in politics and business. Since the time of Bismark, retirement and subsequent pension has been 60-65 years in most developed countries, but in the 1800s most older people did not survive past 47 years to enjoy the benefits of the pension. Older people in developing countries can now expect to reach at least 65 years, and in the developed world pass it by 11 years (*World population prospects*, 2004).

Hand in hand with the altered attitudes of the population goes the authority and ability to make decisions, with particular reference to health. The paternalistic approach to medicine is rapidly giving way to an 'independent choice' model with an emphasis on patient autonomy. This model is different from 25 years ago when the physician exclusively made the decisions, to the present-day where the physician is more of a guide, providing knowledge and encouraging discussion (Quill & Brody, 1996) (USA). Not only are there differences between time periods, there are also differences between present day generations. These generations will all one day be the oldest generation, but when that time comes their needs and wishes will be vastly different. The generations can be divided into four distinct cohorts, which fall in approximately 20-year time gaps. Generalisations can be made to show the differences between the four groups, as in Table 2.1 and Table 2.2 (Gaylor, 2002) (USA). The youngest of the cohorts is Generation Y (sometimes called Millennials or echo boomers) born between the period of 1982 and 1995. These young adults have learned how to multi-task with cell phones, internet and are totally conversant with the worldwide community. Generation Y aims to please and enjoys teamwork and community service. Generation X, born between 1961 and 1981 are more independent, but are also conversant with technology. People born post World War 11, prior to 1960 (Baby Boomers) are driven and dedicated and are part of a 'nuclear family' where father knows best. The oldest generation born during or before the war, is called the Silent Generation. This generation has had an autocratic style of living where, for example, the doctor knows best, children should only speak when spoken to, and one doesn't question elders.

The attitudes of the Silent Generation compared to the Baby Boomer generation are very different. Some of the differences are in the ways that they express themselves, their attitudes to authority, and job attitudes. The Silent Generation expected the father to stay in the one job for life and the mother to look after the children and not have outside employment.

Table 2.1: Generations and their themes

Silent generation	**Baby boomers**	**Generation X**	**Generation Y**
Hard work	Personal fulfilment	Uncertainty	What's next?
Duty	Optimism	Personal focus	On my terms
Sacrifice	Crusading causes	Live for today	Just show up
Thriftiness	Buy now, pay later	Save, save, save	Earn to spend
Work fast	Work efficiently	Eliminate the task	Do exactly what's asked

Constance Alexander. Digitaledge.org/monthly/2001-07/gengap1.html#matures

Table 2.2: Generational assets and liabilities

Silent generation	Baby boomers	Generation X	Generation Y
Assets			
Stable	Service oriented	Adaptable	Collective action
Detail-oriented	Driven	Techno-literate	Optimism
Thorough	Go the extra mile	Independent	Tenacity
Loyal	Good at relationships	Not intimidated by authority	Heroic spirit
Hard-working	Want to please	Creative	Multi-tasking abilities
	Good team player		Technology savvy
Liabilities			
Inept with ambiguity and change	Not naturally budget minded	Impatient	Need for supervision and structure
Reluctant to buck the system	Uncomfortable with conflict	Poor people skills	Inexperienced, particularly handling difficult people issues
Uncomfortable with conflict	Reluctant to go against peers	Inexperienced	
Reticent when they disagree	May put process ahead of result	Cynical	
	Overly sensitive to feedback		
	Judgemental of those who see things differently		
	Self-centred		

www.agts.edu/faculty_publications/articles/creps_generations-charts.pdf

The changes within the New Zealand population

If the 20th century is remembered as the 'Century of Youth' for its creative youth-culture and mannerisms, the 21st century may be remembered as the 'Century of Older People' with such a high proportion of the population over 65, and many people living for 20 years or longer in retirement (Koopman-Boyden, 1993). New Zealand's population is following along in the trends of the world figures, and ageing. This is measured by the growing size of the proportion of older people and its increasing share of the total population. The number of people in New Zealand over the age of 65 has more than doubled since 1951 to reach almost half a million by the 2001 Census (Khawaja & Thomson, 2000).

Between 1996 and 2001 not only was the total population of New Zealand over the age of 65 years increasing proportionally, there was an even more dramatic increase of 33 percent of people over the age of 85. The increase of 15 percent for 75 to 84-year-old people was less dramatic (Davey & Gee, 2002). Over the next 50 years it is projected the over 65-year-old population will more than double to an estimated 1.18 million, peaking in the late 2060s at 1.23 million (Khawaja & Dunstan, 2000). The Baby Boomer cohort will provide the largest increase in people over 65 in the years between 2021 and 2031. After this there will be a slow and steady decrease to 2101 when it is estimated that the over 65-year-old population will again be below the 2050 level at 1.15 million.

New Zealand in 1975 and 2000 along with Australia and Canada had one of the lowest percentages of over 65-year-old people among the OECD countries. The projections for 2015 and 2030 place New Zealand well below all other comparable countries in the percentages of people over the age of 65. However by 2030 the percentage of people over 80 years in New Zealand, will change to be amongst the highest countries (Kinsella & Velkoff, 2001). It is not surprising looking at the median population age of the OECD countries that New Zealand sits at the lowest at median age 32 in 2000. In the projections the median age will be 39 in 2015, and 40 in 2030 for New Zealand (Kinsella & Velkoff, 2001). The New Zealand Statistics Department's figures vary slightly for the median age at 34 in 2000 and have projected the median age at 2050 at 45 years (*Changing age structure for older population*, n.d.). It is further highlighted by the comparison between the 1901 median age of 22, compared to 100 years later when the median age was 35. Only 50 years later the median age will again rise by 10 years to 45 (Ministry of Economic Development, 2003).

The reasons for New Zealand's growing ageing population can be divided into two aspects: The first relates to structural changes where the proportion of the older people's increases is caused primarily by falling fertility. This can be demonstrated by examining New Zealand's fertility rate at its peak in 1961 (4.3 births per woman), compared to 2.00 births in 2005 (*Births summary of latest trends*, n.d.), with the projection for further falling of this number in the coming years. Along with the USA at 2.04 births per woman, this is the highest birth rate for OECD countries (Kinsella & Velkoff, 2001), although Statistics New Zealand information puts New Zealand as 4th equal with the USA, after Mexico, Turkey and Iceland (Statistics New Zealand, 2003). The replacement level for births is calculated at 2.10; consequently all the developed countries are now sub-replacement fertility levels. One can ponder on the effect of the delaying of child bearing from the median age in 1971 of 25 to the median age in 1999 of 30 (*Who are the 65-plusers?*, n.d.).

The second reason for the ageing population is numerical, which is an absolute increase in the number of older people, primarily attributed to an increasing life expectancy (Ministry of Economic Development, 2003). Some relate the demographic shift primarily to the large cohort of Baby Boomers moving into their retirement years, and say the rising life expectancy and declining fertility is only exacerbating this effect (Davis & Fabling, 2002). Life expectancy, or the number of years from birth to death, has increased over the last 50 years by 2.7 years for males and 4.2 years for females, which brings the total number of years to 81.5 and 84.9 years respectively (*Older New Zealanders - 65 and beyond*, 2004). Another measure of the older population is their ability to function, participate and live independently in society after the age of 65. Both males and females can now expect to live 57 percent of their lives after 65 independently, although it should be noted the life expectancy for males is shorter.

The living arrangements of older people are also changing, with more people choosing to live alone. The percentage of older people living alone is 42.6 for females and a much lesser number for males at 19.9 percent. Since the 1960s few older people live with their children, possibly due to decreasing family closeness, greater geographical mobility, greater prosperity, or more supporting services within the community. This proportion is likely to grow as the numbers of childless working-age people increases (Fletcher & Lynn, 2002).

The policies, funding and providers of services for older people

The providers and funders have found it necessary to put new policies in place to cope with the population ageing, to ensure that the older people will be well supported. The predicted fiscal implications of the ageing population are: (i) a declining labour force; (ii) lower economic growth and tax revenue; (iii) higher per capita health and superannuation expenditure, all leading to; (iv) an increase of approximately seven percent in the gross domestic product (Davis & Fabling, 2002). Increased longevity does not necessarily mean that health services will be required over a longer period. The greatest need for health services occurs during the last three to four years of life, regardless of the age of the person (Office for Senior Citizens, 2003). Contrary to this argument is the continued increase in the number of people with dementia, a significant health and service issue. With the prevalence of people with dementia doubling each 5.1 years between the ages of 60 and 90, it is predicted that between 1992 and 2016 the prevalence will increase by 96-100 percent. At present 7.7 percent of people over the age of 65 have dementia. The rapidly developing pharmaceutical industry, which has so far delivered major benefits to older people, can be expected to continue to develop new products for this condition (Office for Senior Citizens, 2003).

The ‘compression of morbidity paradigm’ introduced in 1980 demonstrated that the period of time an older person may have a disability could be one of two scenarios: (i) a longer period of disability, if the mortality is increased and the onset of morbidity remains the same; (ii) a shorter period of disability if the morbidity extension moves more rapidly than the mortality (Fries, 2003) (USA). Trends in mortality have not increased as predicted in the 1980s, but if present trends continue, the gains in life expectancy after 65 years will be modest.

However, the same is not true for morbidity which has declined by approximately 2 percent per year (Freedman et al., 2002; Fries, 2003) (Figure 2.1).

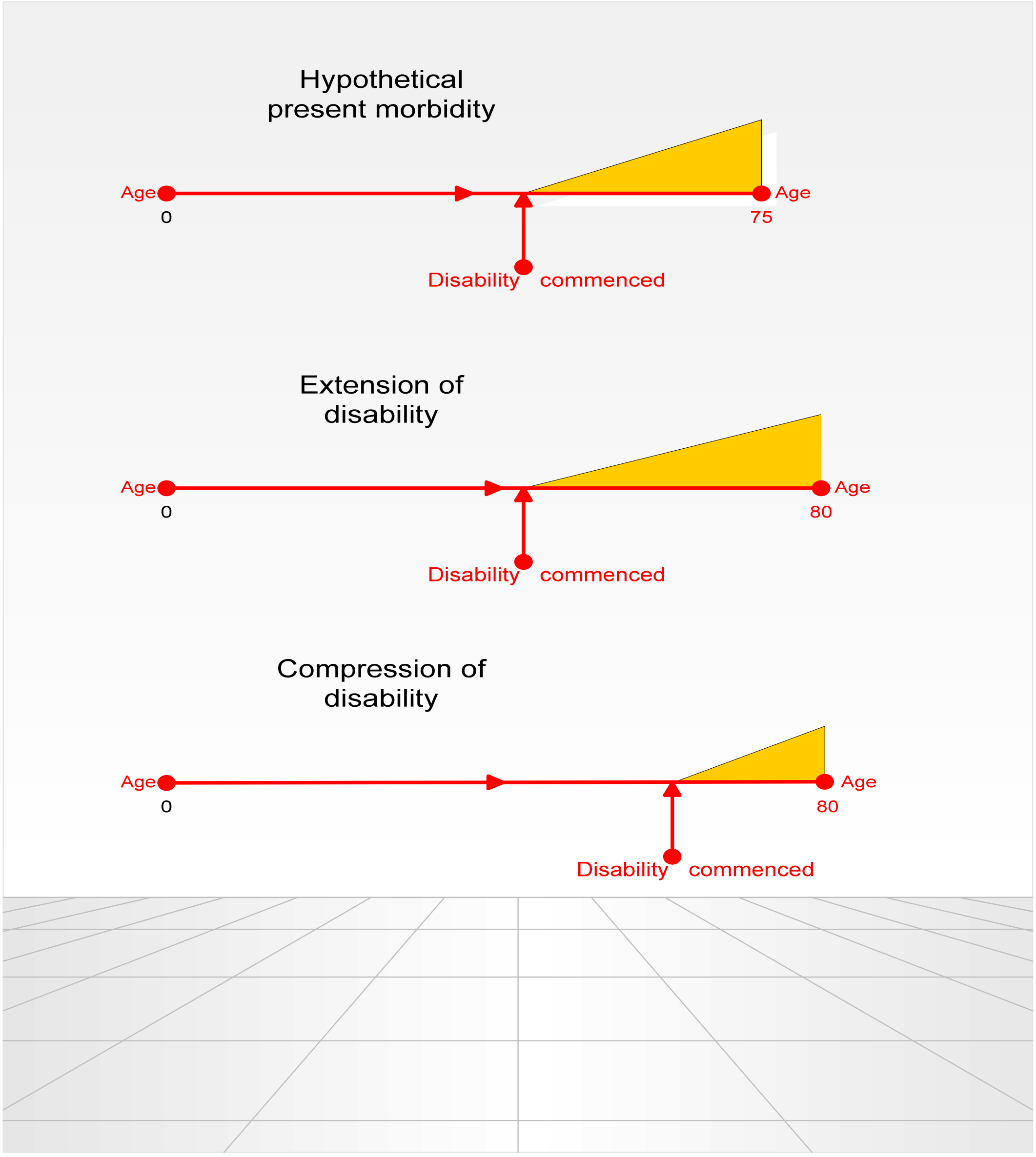

Figure 2.1: Possible scenarios for mortality and morbidity. Adapted from (Fries, 2003)

Perhaps the success of modern medicine is the transformation of acute causes of death into chronic illnesses. Health care now is enabling people to survive with implacable illnesses, few stable and many progressive, and taken together all eventually fatal (Lynn, 2005) (USA).

The New Zealand ‘Positive Ageing Strategy’ initially launched in 2001, promotes the Government’s strategic plan for older people. The main aims are: “*to improve the opportunities for older people within the community, in the way they choose*” (*The New Zealand positive ageing strategy: Towards a society for all ages*, 2001, p. 6). Another policy which sits along side this is the New Zealand Disability Strategy, which has a vision of: *“a society that highly values lives and continually enhances full participation”* (Ministry of Health, 2001b, p.1). These policies cover the ‘Health of older people’s strategy’, which sets out the future direction of health and disability support services for the older population. It has the vision of older people participating in decisions about their health, well-being and family life.

As part of the health strategy in 2003, a number of Ageing-in-place (AIP) initiatives, providing community support options other than residential care, were set up across the country (Ministry of Health, 2003b). It is interesting to note that the financing of formal home support remains limited. This could be, as pointed out in the paper by Pezzin et al (1996) because of concerns that subsidies for home support will substantially increase the overall public long term support expenditure without the benefits of lowering the residential care use. Also there is a worry that the publicly funded home support will substitute the support given by the family (at no cost to the Government) rather than supplement it. The older person in the later scenario is no better off with the provision of their support (Pezzin, Kemper, & Reschovsky, 1996) (USA).

Policies to improve lifestyles of people, such as reducing smoking and improved diet, are involved in the decline of coronary heart disease and possibly making the manifestations of cardiovascular disease milder. Cardiovascular diseases are a major cause of death in New Zealand and account for 44 percent of all deaths.

Eighty seven percent of those people were over the age of 65, of which stroke, coronary heart disease and hypertension were the most common causes (Bonita & Beaglehole, 1998; Fletcher & Lynn, 2002). Also included in the health and social welfare policies is the move to improve the housing for older people, which in turn will improve their health status (Howden-Chapman, 2004). The provision of health support services will need to change focus to the chronic diseases, including osteoporosis and arthritis, rather than acute illnesses, to accommodate the ageing population (Binstock et al., 1996; Wiener & Tilly, 2002) (USA). An adjunct to the ageing population is the increased extent of long-term disability in younger people with complications of AIDS. They will require long-term support services such as residential care or home support services, with these implications also encompassing funding and policy.

Funding the services has been proposed as a major implication of the ageing population (Schulz et al., 2004) (Germany). An Australian paper suggested that a large proportion of the costs are incurred by the dying process, in the last couple of years of life (Coory, 2004). If the funding calculation were taken from the number of years from expected death, as suggested by both Coory (2004) and Sanderson (2005), this would vastly improve the forecast for the increased funding. This could be done by avoiding the extended years of relatively service-free life of the older person by just concentrating on the last two years where most of the expenditure is used (Sanderson & Scherbov, 2005). However the gains from this calculation may be offset by the increase in the expenditure on the younger elderly, those with complications of AIDS, and the increased numbers of older people with disabilities (Binstock & George, 2001; Lakdawalla et al., 2003).

For the four years prior to 2000, there was an average yearly increase in Government spending for residential care of 5.5 percent to total $426 million (Fletcher & Lynn, 2002). The total New Zealand Government expenditure on residential care services comprised 56 percent of the Disability Support Services budget for 2002/2003 (Ministry of Health, 2003a). The percentage of older people who go into residential care has remained relatively constant, at 6 percent over the years; but the residents now have higher support needs. The increase in spending is related to the growth in utilisation. With these increases and predicted increases, it is important to consider the societal costs of residential care in conjunction with the increasing number of beds, and the increasing number of people over 75 years. More community or home-based support could be one possible solution to the ever-increasing residential care needs. There is a diversity of opinion about the costs of home-based support, with some research finding that this does not substantially reduce the costs over time (Miller & Weissert, 2000) (USA); conversely others have found that it is a less expensive alternative to institutional care (Belgrave & Brown, 1997).

Following along from the deinstitutionalisation of the people within mental health, and child welfare and disability support in New Zealand, the provision of community services for older people within the community has increased particularly since the 1980s (Belgrave & Brown, 1997). In June 2005, the focus of the referrals to residential care was changed by the Ministry of Health in an effort to maintain more older people within the community in their own homes, rather than residential care entry.

> *A person is referred for residential care when the service co-ordinator is unable to put together a package of community care to support the older person to live safely in the community. Entry into DHB funded residential care is not therefore an entitlement arising from a person being assessed as having a certain level of need* (Ministry of Health, 2005, p. 4)

Older people are therefore assessed as requiring a level of need and a support package is put together to meet that need, considering both safety and cost. Residential care will be a last resort, used only when the older person’s needs cannot be met in the community (Ministry of Health, 2005).

It is generally recognised that as people age there is a correlation with an increased amount of support needed. Nearly half the older Americans, for example, have a non-fatal disability such as arthritis. With mortality decreasing due to the improvements in the treatment of acute disease, the consequences are an increase in the rise of older people with disabilities, and therefore the need for more support (Binstock & George, 2001) (USA). A future trend for decreased mortality from stroke (which is the second highest cause of death worldwide and the third highest in the developing countries) has been suggested, which would also increase the number of people with disabilities (Feigin et al., 2003) (NZ). Increased longevity, due to the elimination of some chronic diseases, actually increases disability, by allowing the development or progression of other more disabling chronic diseases (Fletcher & Lynn, 2002) (NZ).

Therefore, population ageing has a direct effect on the potential support ratio (PSR), or numbers of people aged 15-64 as compared with those 65 years and over. In the 50 years prior to 2000, the PSR fell from 12 to 9 persons per each older person, but in another 50 years it is predicted to fall to 4 working age people to every person over the age of 65. Examining the oldest of the old (85 years and over) compared with the age of the people who would historically be their caregivers (50-64 age group), this ratio was 4 per 100 caregivers in 2000, and is expected to rise to 11 per 100 caregivers in 2050 (*World population ageing*, 2002).

Support services for older people

At some stage in the majority of older people's lives they need the assistance of some form of support, whether it is gardening, housework, equipment, or personal cares. Support can be provided in a variety of places such as at home, or within residential care and in many different forms depending on the requirements of the older person and their caregivers.

There are two interesting observations from the ageing population, firstly that there is now a ‘sandwich generation,’ the mid-lifers who have both the younger and the older generations to provide support for, where in past centuries the life expectancy of the older person would not usually permit this (Hillcoat-Nalletamby, 2002; Kinsella & Gist, 1998; Spillman & Pezzin, 2000). Secondly, the older person is also being required to play more of a major role in caring for children and grandchildren, especially in Africa where millions of AIDS patients are supported at home by their elderly parents. Therefore, when discussing support it would be appropriate to say that even though the population is ageing there is an increasingly important role for the older people themselves as caregivers. The support is increasing both upwards from children to parents and downwards from parents to children (World Health Organization, n.d.).

The meaning of home to the older person

Home can be defined as the domestic dwelling as well as the general area or locality in which a person lives. The person living at home has networks of friends and neighbours built up over many years and providing support and a sense of social identity (Reed, Payton, & Bond, 1998) (UK). Home is usually perceived by the older person as one of the major focuses in their life, and becomes of greater importance as the other distractions, such as employment, fall away. It is also a private place which is the centre of domesticity, intimacy and memories, and is surrounded by community interactions (Bond, Coleman, & Peace, 1993) (UK). Older people have a deep attachment to their homes which has been linked with ontological security (S. Dwyer, 2005; Reed et al., 1998) (UK).

Home has been described as an important element in ‘quality of life’ where it was found that living at home was more important than health (Farquhar, 1995) (UK), and the loss of a person’s home is akin to a bereavement (Tinker, 1997) (UK). The bulk of the ageing population will be women who are also more likely to be disabled than men. It has been reported they are more dissatisfied with their housing in older age, which has been attributed in Britain to poorer housing for women (Tinker, 1997) (UK). This has not been shown to be true in New Zealand. However, home did not gain the same high significance in the qualitative study of 11 older people in Sweden (Borglin, Edberg, & Hallberg, 2005) (Sweden). A concept of 'place,' while not specifically being called home does add an important dimension to the theory of person-environment relationships. It can include the conceptual pillars of place such as sense of place, place identity, place attachment and place integration. However it is an ambiguous concept because, as well as home, place can also refer to areas of different scale and meaning, such as region, town or neighbourhood (Cutchin, Owen, & Chang, 2003) (USA). From a study of older people in 1990 in the UK Sixsmith developed three themes to underlie the meanings that older people generally associate with home. The first was that home was the major focus in life, the second highlighted the need for independence in the home, and third that older people had a strong attachment to their homes and their memories there (Bond et al., 1993). It is evident that these three things are taken away when the older person is moved, particularly to an institution.

The concept of home is wide, and can encompass a large estate with house and gardens, a townhouse with or without gardens, or an apartment usually without gardens. It also is an individual villa or serviced apartment within a retirement village, or a room in a community house where older people jointly live with oversight from a manager. Conversely the room in an institution where the older person lives must also be classed as their home under the Oxford dictionary definition of home, "*a place where one lives; fixed residence.*" For the purpose of clarity in this document, only non-institutional residences have been described as home. The majority of older people do live in their own homes, with 75 percent being women, and approximately 33 percent living alone (Office for Senior Citizens, 2003). The ability of older people to remain independent at home relies on major factors such as housing, transport, support services, access to the community, safety and security and contact with family and friends. Remaining at home is seen as a key factor for the older person to maintain independence. Moving house or from the 'family home' is seen by many people as a rare occurrence, although it was found to become more of a prominent feature in later life (Reed et al., 1998).

Home-based support for older people

When considering community support, the first issue to be raised should be that of the older person's dependence and their acceptance of that state. In the 17th century John Donne wrote that: "*no man is an island unto himself and that when the bell tolls for one it tolls for all*" (Cantor, 1989, p. 101).

Mutual interdependence acceptance varies from society to society, but in the developed nations such as the USA (and possibly New Zealand); the pioneering spirit has stressed the need for the individual to cope with as little assistance as possible, except at the beginning and end of their life. The older person deals with this dichotomy by being 'self-sufficient' within one's family, thus leading to the large numbers of family assisting older people. It is only when families are no longer able to cope with the demands and needs of the older person that they seek formal assistance (Cantor, 1989).

Support for the older person within the community is varied and can be social, physical, environmental and medical support. This can be either informal, usually by a relative (spouse or child), or formal, provided by paid workers funded privately or through the District Health Boards (DHB) or ACC. Most support comes from informal sources (Power, 1989) (UK), but there appears to be a perceived hierarchy of preferred caregivers. The spouse rates highest as preferred support worker, and then the daughter. The daughter, often unmarried, has felt the family and social pressures as the social networks decrease with the older person's increased physical and mental deterioration (Belgrave & Brown, 1997; Jefferys, 1991; Koopman-Boyden, 1981; Office for Senior Citizens, 2003) (NZ). The support from the family, the largest provider of informal support for the older person, has changed little today in the nuclear family from the 19th century, when the families comprised of one generation of parents and their children. The families of today could be called ‘modified extended nuclear families’ where family ties operate beyond the household and work on a principle of revocable detachment, support as and when needed (Connidis, 1989) (Canada).

Informal support provides a huge economic and social contribution with almost 846,000 people in New Zealand providing support for someone in need (Milligan, 2004; Opie, 1995). When looking at the cost of informal support in 1997 in both rest homes and community support, the cost of informal support per person per week in rest homes was estimated at $67.29, and in the community $110.69 (Belgrave & Brown, 1997). The total value of informal support has not been estimated in New Zealand, but as an example of the huge savings to the Government, in the UK in 1998, the overall value was estimated at 34 billion pounds (Milligan, 2004).

There are problems which can arise from supporting people in their own homes, such as the physical and mental condition of the older person being compromised, or the physical or mental condition of the support worker suffering. Sixty-six percent of caregivers had suffered some effects on their own health, but it is unknown what ill-effects the older person suffered from the support given by these people (Koopman-Boyden & Wells, 1979) (NZ). Caregivers in New Zealand also have long-term financial disadvantages, especially for women, such as loss of savings and lack of income to purchase their own home, although this is not recognised as a major source of strain for the caregivers (Belgrave & Brown, 1997) (NZ). However, research in both New Zealand and the USA has shown strong support networks, such as the informal caregiver, can have many benefits including diminishing the likelihood of the older person entering residential care (Bear, 1990; Boaz & Muller, 1994; Keeling, 2001) and assisting with the health and disability support plans for the older person (Litwin, 2001) (Israel).

As a general rule, the level of disability and therefore support needs, increases with age (M. Dwyer, Gray, & Renwick, 2000) (NZ) and is managed either within the community environment with support, or within institutional living. Although

92 percent of people over the age of 65 in New Zealand live independently and 87 percent of people aged over 75 live independently, the older people with high and complex health and disability support needs are a very distinct cohort within our society. The Ministry of Social Policy has defined a disability as any limitation in activity resulting from a long-term condition or health problem (M. Dwyer et al., 2000). In the group of people aged 65-74 living at home, 74 percent were managing without assistance. Only 54 percent of those aged between 75-84 and an even smaller percentage of 15 percent of those aged over 85 years were managing without assistance (Fletcher & Lynn, 2002). The growing number of older people has brought about changes in attitudes and policies, with the basic concept of community support as one of assistance to augment individual competency and mastery of their environment, rather than increase the dependence of the older person.

The history of residential care of older people within New Zealand

Not only has housing changed in the past centuries, but housing policies for older people have taken a more prominent place. Winston Churchill said in 1943 in a speech to the House of Commons: *"We give shape to our buildings and they in turn shape us"* (Howden-Chapman, 2004).

Many older people in the 19th century had no families to support them, so this resulted in institutional life when support was needed. Institutional support swung from 1908 to 1948 where the larger public hospitals took the responsibility of supporting the older people (Jefferys, 1991). In the mid 20th century the majority of older people had families, but familial dependence was not popular, which again resulted in high residential care entry. During this period also the social policy was moved way from income maintenance, such as age benefits, to social service provision, with the Government subsidising service provision. Charitable aid re-emerged and began providing both institutional and community services. By the 1950s religious and welfare organisations were building accommodation for older people. In the late 1970s and the early 1980s the growth of the profit-making sector emerged to provide residential care which encouraged a slow shift from public hospital provision of aged support, to the private and religious and welfare sectors in New Zealand (Koopman-Boyden, 1993).

Long-term support of the older people remained mostly in the domain of the public hospitals until the health reforms of 1993 when the Government restructured the hospitals into business units, and separated the funding from the provider arms (Ashton, 2000) (NZ). This accelerated the move of the public hospitals to subcontracting the support of the older people with high support needs back to private residential care organisations such as residential care. Residential care for older people is defined as: "*a long-term care facility from the full range of socio-economic, educational, professional, religious and geographic backgrounds*" (Lee et al., 2002, p. 19) (China).

In 2004 there were very few public facilities providing residential care for older people. There were reducing numbers of religious and welfare institutions, and increasing numbers of private profit-making businesses investing in the aged care market.

The ageing 'Baby Boomers' will result in an increase in the number of long-lived older people, which may lead to an increase in the need for residential care. While the older people are the main users of residential care now, this population will change and also increase in 20 years time when younger people with chronic and medically complex condition such as AIDS will be classified as 'old' and also tax the supply of beds (Bhattacharya et al., 2004; Binstock et al., 1996; Lakdawalla et al., 2003) (USA). It is predicted by some that the biomedical and clinical breakthroughs will not be sufficient to cure the three most disabling conditions of the present older age, dementia, osteoporosis and osteoarthritis, and therefore will not affect the occupancies of residential care institutions (Binstock et al., 1996) (USA).

It has been suggested (Manton, 2003) (USA) that there is a negative correlation between cognitive exercise, educational standards, the use of oestrogen, ibuprofen (or other equivalent drugs), the improved management of sensory impairment such as vision, and severe cognitive impairment. Further studies need to be done on the significance of these effects. Drugs which improve the availability or the effect of acetylcholine, a neurotransmitter in the brain, may delay the deterioration of cognitive impairment, but are merely of temporary benefit (*Dementia in New Zealand*, 2002). Similarly, the decline in certain types of arthritis with the use of disease modifying agents such as methotrexate has been argued (Manton, 2003). However it would seem clear that these drugs cannot reduce the actual condition of arthritis, but merely relieve the condition. Nevertheless all these effects may contribute to the reduced incidence of acute and chronic disability, and may in the future reduce occupancies of residential care institutions, contrary to the above claim by Binstock et al. (1999) and the fiscal predictions given earlier in the chapter.

Residential care for older people is available in most of the developed countries, but with slightly different names. For example, nursing homes and hostels in Australia, chronic care or rehabilitation hospitals, and extended care facilities or nursing homes in Canada and America, long-term geriatric hospitals and nursing homes in England and Sweden, and Germany with specialty hospitals, nursing homes and old age homes (Abrams, Beers, & Berkow, 1995). However residential care for older people has not always had a good name, or been a place where older people would choose to go. Residential care has in the past been compared to other institutions such as prisons or monasteries, described as ‘people processing organisations’ which create compliance to the institutional regimes (Fennell, Phillipson, & Evers, 1993).

Relocation for the older person can be a serious matter. If the older person has developed and maintained a sense of self through their home, a relocation will disrupt their sense of self in their environment, especially if the move is to a different geographical area (Reed et al., 1998).

The question has often been asked why would older people enter residential care when relocation in later life has been said to precede depression, increasing dependence and dislocation from friends and family (Lee et al., 2002; Milligan, 2004; Morgan et al., 1997; Nay, 1995; Nolan et al., 1996). Residential care has been the choice of some older people as the safe haven that is required for their abilities and disabilities (Miller & Weissert, 2000) (USA). It has given their primary informal caregivers some respite from the continuous and often arduous tasks of the 24-hour support of the highly dependent older people in New Zealand, as illustrated by this quote: *"I couldn't cope day and night, and he wouldn't have anybody else in the house. So I had to sign the papers…*" (Milligan, 2004, p. 50). Older people who are lonely at home also choose to enter residential care to enjoy the increased social contact that this environment provides (Mirotznik & Kamp, 2000).

The percentage of people entering residential care is very small at 6.3 percent within New Zealand (Fletcher & Lynn, 2002), and most of the support needed by the older person is provided by friends and families at home (Milligan, 2004). It is of some concern, however, that 25 to 30 percent of all people over the age of 65 will experience residential care prior to death (Flicker, 2000; Kinsella & Velkoff, 2001) (Australia). For those women over the age of 85 in the UK the odds are almost even of the chance of entering residential care prior to death (Bebbington, Darton, & Netten, 2001) (UK). Long term support for older people is monopolised by residential care in terms of resourcing, complexity and public profile, and therefore some form of residential care will always have to be available to those not able to be supported in their home environments (Office for Senior Citizens, 2003).

2.4: Part 1 summary

The changes in the population both worldwide and in New Zealand due to low levels of fertility and increased longevity have led to population ageing. This is having, and will continue to have significance for the older person, particularly those who need high levels of support. As well as the changes to the population structure, the attitudes and desires of the people are changing with time, as demonstrated by the differences in the four generations, the Silent Generation, Baby Boomers, Generation X and Generation Y. Government policies are reflecting the changes by starting to provide more innovative services within the community and restricting residential care entry where possible.

Part 2: Risk factors for entering residential care

> *None are so old as those who have outlived enthusiasm*
>
> Henry David Thoreau 1817-1862

The review of the literature in Part 2 examines what factors have influenced the decisions surrounding older people entering permanent residential care. Factors which lead to residential care entry are many, and often mixed with other contributing influences. Most articles differ in the combinations or importance of the factors. For many factors there are articles which promote and refute that claim and cite others instead. The word ‘risk’ has been used when discussing entry into residential care because most literature relates the older person’s dislike about the thought of having to ‘go into a home’.

The trend is for increasingly frail people with highly specialised needs, including high levels of cognitive impairment, to be admitted to residential care (Davies & Nolan, 2006) (UK). This demonstrates the embeddedness of services even with the incremental shift towards community services (Dulmus & Rapp-Paglicci, 2005) (USA). There is, however, a shift towards choice and empowerment for older people which is linked to the Government’s Ageing-in-place (AIP) policies.

These policies will result in a shift in the philosophy of support from residential care to community support.

Risk factors for residential care entry can be any serious physical, cognitive or psychiatric disability, but equally important is the lack of services currently provided in the home.

> *The greatest risk factor for residential…placement is not the presence of a disabling disorder…but the absence of services and supports known to maintain people in their homes* (Dulmus & Rapp-Paglicci, 2005, p 401)

There have been many articles written about the risk of entry to residential care and the factors which are involved in its entry, but Miller et al. (2000) in the USA have provided a substantial literature review of articles written between 1985 to 1998 which form a 'prediction' list (Miller & Weissert, 2000). Others have subsequently written major findings which contribute to the overall knowledge of factors involved in residential care in countries such as Britain, America and Australia, but there have been few articles found which refer particularly to New Zealand. However, one New Zealand study looks at the Needs Assessment Service Co-ordination (NASC) referrals noting which people the service referred to residential care, and to their entry factors in general (Weatherall, Slow, & Wiltshire, 2004.). Another New Zealand study to determine if Assessment Treatment and Rehabilitation Units' (AT&R) assessment was necessary prior to residential care admission did not determine the entry factors (Wilkinson & Sainsbury, 1992).

In 1973 Anderson and Newman first coined the words 'predisposing', 'enabling' and 'need' factors, as a way of clarifying and dividing the risk factors for the older person entering residential care (Miller & Weissert, 2000). Predisposing factors have been described as characteristics which are usually exogenous of individuals and include demographic, social support and health belief indicators. Enabling factors affect the decision-maker and include indicators of familial and community resources. Need factors identify the older person's vulnerability (such as having dementia), which could be addressed by residential care entry.

The division of factors into these three headings is somewhat confusing, due to the great diversity of the factors in the articles and their placement within the divisions. The conflicting nature of some of the factors listed by articles can be seen in the example of gender. 'Being female' is listed as a predisposition factor (Kersting, 1994; Palmore, 1976), but 'being male' is also listed as a predisposition factor (Bauer, 1996; Lakdawalla et al., 2003). Because of the longer lifespan and a large percentage of the over 85-year-old people entering residential care, it is understandable that there will be many more females residing in residential care. However, the actual percentage of older males entering residential care compared to those males living at home is higher than a similar comparison for females. Some US authors have identified financially poor people as being more likely to enter residential care, partly because they could not afford home help and medical care (Lakdawalla et al., 2003). Others felt that those with money could afford to pay the fees for residential care (Palmore, 1976). Being of European descent ('white') was mentioned by several as being a risk factor for residential care entry (Black, Rabins, & German, 1999; Kersting, 2001).

2.5: Advanced age as an indicator for residential care entry

Most studies have shown advancing age to be a significant and consistent predisposing factor for entry into residential care (Miller & Weissert, 2000; Shapiro & Tate, 1985; Wolinsky, Callahan, Fitzgerald, & Johnson, 1992) (USA). This is emphasised by women over the age of 85 years having just under a 50 percent risk of residential care entry (Bebbington et al., 2001) (UK). The percentage of people admitted to residential care increases with age, rising from 1.3 percent for the 65 to 74 aged group, 5.7 percent for those older people aged 75 to 84 and the alarmingly high 24.5 percent for all people aged 85 and over (Ministry of Health, 2001a; *New Zealand now: 65 plus*, 1998). Of the total residential care population, 56 percent are women, and also 50 percent of people in residential care are over the age of 85. The number of people over the age of 85 has increased by 33 percent in the years from 1996 to 2001, but the increase is not so marked (at 15%) for those people aged 65 to 84 (Davey & Gee, 2002). However, because a person is very old does not mean that all people over the age of 85 will be at risk of residential care entry (Shapiro & Tate, 1988) (Canada). For people aged from 65 to 84, three or less activities of daily living (ADL) problems would make residential care entry unlikely (Shapiro & Tate, 1988).

Age and education were found to be predictors of residential care, but only when there was decreased cognitive performance. However, the importance attributed to basic physical functioning status in relation to residential care admissions may well be overrated; many people in the community have equal to, or more disability than people within residential care (MacNeill, 2000) (USA). In a longitudinal study of 3,383 people over seven years, it was found that the significance of increased age and ADL problems decreased over time, and with the very old these factors were no longer significant predictors of residential care entry (Shapiro & Tate, 1985) (Canada). Also a New Zealand study of 200 older people in institutional care did not consider age or co-morbidity to be a predictive factor (Wilkinson & Sainsbury, 1992).

2.6: Loneliness as an indicator for residential care entry

Loneliness in the retirement years could be related to the sudden loss of a spouse or family, or the loss of the primary support person (Lee et al., 2002) (China) especially in men (Tomiak, Berthelot, Guimond, & Mustard, 2000) (Canada) which could also lead to the need for the return of security of support and therefore be seen as predictive factors for residential care entry. Many studies concur that loneliness is one of the major predisposing factors for admission to residential care (Devroey, Van Casteren, & De Lepeleire, 2002; Palmore, 1976; Wolinsky et al., 1992). Loneliness in itself is not a predictor of residential care entry, but the older person who is lonely, or living alone with high support needs is much more likely to enter residential care than those living with others (Russell, Cutrona, de la Mora, & Wallace, 1997) (USA). An English household survey in 1994 it was found that 73 percent of older people living alone received community needs support and 64 percent of the admissions to residential care were from people living alone (Bebbington et al., 2001). While living alone is not synonymous with being lonely, it is far more likely in this situation. New Zealand’s figures for older people living alone are similar to those of the USA, where almost one third of people over the age of 65 are living alone (Khawaja & Thomson, 2000). Of more concern are people over 85 years where the percentage of women living alone is 68 percent (Abrams et al., 1995; Kinsella & Velkoff, 2001; *New Zealand now: 65 plus*, 1998; Office for Senior Citizens, 2003).

Many older people express a keen desire to maintain their independence and not be a bother to others. While living alone may be a choice, there is the possibility that loneliness or the negative feelings about the quantity and quality of social contact may develop. Two types of loneliness can be found; the emotional loneliness which is the lack of an attachment figure such as a spouse, and the social loneliness, which describes relationships with others (Abrams et al., 1995; Havens, Hall, Sylvestre, & Jivan, 2004) (Canada). The death of a spouse is the most potent predictor of loneliness among older people (Russell et al., 1997) (USA). In the cohort of people with high or very high support needs, the likelihood of social isolation and loneliness is much higher, and while social isolation is often associated with loneliness it is not always the cause (Havens et al., 2004; Wenger, 2004). In an article from the United Kingdom Times, a director for a charity said:

> *We far too often shunt older people into the sidings of life, leaving them without enough money, activity, but above all, human warmth* (Smith, 2005, p.4)

This could lead to an argument for residential care entry where increased social interaction between older people has in some situations led to an improved health status and alleviated loneliness (Donaldson & Watson, 1996) (UK). However, increased social interaction within the community may well achieve the same effect.

Some historical theories which have now been largely discounted promoted ageing as a gradual withdrawal from society, thus leading to loneliness. The ‘disengagement theory’ (developed by Cumming in 1960) stated that for older people who were in good health, with enough financial resources to live independently under normal conditions, ageing was a withdrawal or ‘disengagement’ (initiated by themselves) from the society to which they belonged (Cumming, 1968). This could have been caused by the thoughts of death, which would come sooner rather than later and there may be ‘no time’ to do things. As the older person ages, they continued to ‘disengage’ and gain greater distance from society as a whole. Measurement of the disengagement can be calculated by the degree of potential disruption to society that would follow the older person’s sudden death. As well as the older person withdrawing, society was seen to withdraw from the older person, which lent credence to the disengagement theory.

No matter who initiates the disengagement, society or the older person, it ends up the same with the older person playing fewer roles, with changed relationships. This theory saw ageing as a socially patterned event within a social structure where it was accepted as normal that the older person would withdraw from social roles in order to maintain the social order. It also proposed that old age was a distinct life stage with activities which differ from the other stages by quality and quantity (Cumming, 1968; Fennell et al., 1993; Schroots, 1996). However, disengagement with family does not necessarily mean disengagement with friends, which appears to be heightened in some instances, and vice versa. This theory may have been relevant in the 1960s, but as our society ages and the law prevents discrimination on the basis of age, many more opportunities have opened for people once considered ‘over the hill,’ or no longer useful members of the working community.

A direct counter to the disengagement theory is the ‘continuity theory’, where older people continue to have the same habits as when they were younger, and any decreases in social interaction are the results of poor health or disability rather than society’s need to ‘disengage’. The ‘activity theory’ was a theory involving the falling away of activities and socialisation in older age. In contrast to the ‘disengagement theory’, the ‘activity theory said there were six stages in life, with each having roles with developmental and culmination periods. Other theories describe eight stages, with the successful completion of each stage adding to the character of the individual. It appears there is a wide range of models and theories regarding the rate and manner of ageing (Mein, Higgs, Ferrie, & Stansfeld, 1998; Schroots, 1996). A key assumption is that energy decreases with age and the older person becomes more preoccupied with self and therefore less responsive to normative controls, thus lessening the disruption and effect on society when the older person dies. This theory has been questioned as being ‘a convenient rationalisation’ for something that is merely expedient, rather than natural and inevitable (Fennell et al., 1993).

Structured dependence on the other hand focuses primarily on the role of financial resources and looks at older people as vehicles of ‘society-created dependency’. This is related to social class with, for example, retirement schemes and residential care, which all lessen the authority and responsibility. With less responsibility, the older person becomes increasingly less able, both physically and mentally (Mein et al., 1998; Townsend, 1981). Structured dependence is one of the life course pathways (pathway out of paid employment) by which people arrive at decisions and destinations in later life. The structure of life in older age is influenced primarily by material circumstances and serious health problems (Blane, Higgs, Hyde, & Wiggins, 2004).

The most positive of the theories developed in 1989, Laslett’s ‘third age’ has the possibility of a new condition of healthy retirement, self-realisation and fulfilment, and describes the latter part of one’s life as the ‘crown of life’. Unfortunately this has not been widely accepted as yet, but can be seen with structured dependence as being at the extreme ends of the dependence spectrum, to independence in old age (Blane et al., 2004; Mein et al., 1998) (UK). None of these studies account for the individual's differences with ageing. Each of these theories promotes ageism, which is the ideology, or beliefs which set older people apart from the rest of society. Older people can be seen as a separate group who need special policies and people to look after their interests, but yet the very fact of being helped can be seen as degrading, similar to seeking out financially poor people to help them (Wilson, 1997) (UK).

The age of retirement has gradually been falling throughout the 20th century, and at the same time the life expectancy has risen, leading to more well older people. It is therefore surprising that large numbers of people have chosen to retire, rather than remain in the workforce. This would lead to the thought that retirement is the result of the power structure of society, not the process of ageing by itself, nor primarily the characteristics of the older person (Wilson, 1997). Retirement can be described as a term which excludes older people from the work force. A post-modern stance could be that older people are often more diverse than their younger colleagues because of their accumulated life events.

2.7: Ethnic background

Many studies mentioned the significantly lower rates of residential care entry for Black Americans, Hispanic, Asian and other non-European descent races. People of European background were 66 percent more likely to be institutionalised than people of non-European background (Bauer, 1996; Friedman, Steinwachs, Rathouz, Burton, & Mukamel, 2005; Palmore, 1976), which could reflect greater access to family groups (Lakdawalla et al., 2003). In New Zealand this could be due to the lower life expectancy of old and very old Maori people (*Differing life expectancy*, n.d.), and the Maori customs.

2.8: Availability of support

As early as 1979, four-fifths of a Christchurch sample of older people, expected to be assisted by their children, with the family assuming the Government would provide for the older person financially (Koopman-Boyden & Wells, 1979). That was the time when discussions surrounding, what is now termed, 'Ageing in Place' commenced, with the cost of geriatric hospital beds at $245 and domiciliary care at $177 per week.(Koopman-Boyden, 1981). However, in 1997 the cost of residential care in New Zealand was $547.29 per week and $202.27 per week for home care (Belgrave & Brown, 1997). The push for domiciliary support was further enhanced by the Mosgiel report suggesting that with 'Ageing in Place' a lot depended on the place itself, and a worthwhile project would be the management of interdependence and social contacts (Keeling, 1999).

The first of the two types of support for the older person is the formal long-term support system, which includes residential and community care. To work alongside the health professionals to maintain this system there is a paraprofessional work-force of nursing assistants, home health and home care aides, personal care workers, and personal care attendants. Unfortunately low wages, heavy and hard working conditions, and a job which society does not value highly makes recruitment and retention of suitable staff difficult. ("Health and Disability Services (Safety) Act 2001," 2001). In New Zealand in 2003 there were an estimated 30,000 semi-skilled people providing home support (excluding the unpaid carers) (Ministry of Health, 2003a). But almost 846,000 people were reportedly unpaid carers (Milligan, 2004). Admittedly not all the carers were supporting the older people. Fifty-seven percent of people over the age of 85 were receiving support in their own homes.(Ministry of Health, 2002a). There is also carer support for relief for short periods of time and environmental support which includes housing and vehicle modifications. Approximately $15 million was spent on environmental support in 1999/2000 to people over the age of 65 (Fletcher & Lynn, 2002).

The second and major provider of support for older people in New Zealand is the informal care provided mostly by women, and usually unpaid. Out of a group of 186 older people the carer's relationship was almost entirely familial, with only one person not a relative. The ages of these carers were predominantly in the 30 to 50 age groups (Belgrave & Brown, 1997). This is the age group where the carer possibly still has children at home, probably is also working outside the home, and also maintaining the family home. Another factor surrounding the availability of the carers is the mobility of the caregiving generation. People are much more ready to change jobs and move outside the vicinity of the family home, which would cause further problems for the older person and the carer.

2.9: Support worker stress

One of the major risks of residential care is the lack of appropriate home and community based support (Dulmus & Rapp-Paglicci, 2005, p 401) (USA). It is therefore understandable that psychological distress was recorded in one-third to one half of all caregivers in Britain, and over half of the caregivers in Ireland (Oyebode, 2003; Ryan, 2000). Caregiving has been cited as being one of the most stressful social situations (Dulmus & Rapp-Paglicci, 2005). In a recent study of 2,200 caregivers in America, 88 percent said the reason they had the older person admitted to residential care was a lack of assistance and skilled care (Buhr, Kuchibhatla, & Clipp, 2006). Breakdown in caregiver arrangements and the need for after hours support have been noted in many cases as giving stress to the informal caregiver. Also, the tasks of formal domiciliary care workers are not flexible enough to cover all aspects of practical and personal care (Power, 1989). Many support worker stressors can combine to produce the need for residential care placement for the older person. These can include the older person’s incontinence, wandering, living apart from the older person and having to balance paid employment and too few resources available (Bebbington et al., 2001; Davies & Nolan, 2003). A predictor of residential care entry associated with caregivers is not living in a multigenerational family where the children or grandchildren can also act as caregivers and assist the older person (Wolinsky et al., 1992; Wolinsky, Callahan, Fitzgerald, & Johnson, 1993) (UK).

2.10: Gender differences

In a study of 1,177 older people in residential care in the USA, the majority (84%) were female (Black et al., 1999), which concurred with other UK studies which noted the predominance of females (Bebbington et al., 2001; Kersting, 1994; Liu & Tinker, 2001). This anomaly is most probably due to the longer life span of the female and more females living alone. There is little difference between the numbers of males and females in the New Zealand general population until they reach the age of 70 and then the gap widens until 70 percent of the people aged over 85 are women, and 80 percent over 95 years of age. The New Zealand situation is similar to most developed countries (Davey & Gee, 2002) (NZ). Interestingly, some studies have stated that unmarried men have a significant predisposition for residential care entry. If age is combined with dementia, men were twice as likely to enter residential care as women (Tomiak et al., 2000) (Canada). The unsubstantiated reason for this was:

> *Men are more likely to enter nursing homes, presumably because they are less healthy than women, conditional on other observable factors* (Lakdawalla et al., 2003, p 14).

In the Minnesota study of 5,789 people with disabilities (mean age of 67.84), it was found that in the over 65-year-old age group, older men had a 23 percent greater risk of nursing home entry than women (Bauer, 1996). However this study was in one American state only and may not necessarily represent other states or other countries. The gender difference was not significant between the ages of 65 and 69, but as the ages increased so did the significance for women to be more at risk of residential care entry increase. Out of the people who lived to the age of 90, some 52 percent of the men lived in residential care at least once prior to death compared to 70 percent of the women (Murtaugh, Kemper, & Spillman, 1990).

Cardiovascular risk could be one measure of the health of the older person and therefore the subsequent risk of residential care entry. Four risk factors make up the cardiovascular risk: high blood pressure, diabetes, low physical exercise, and smoking. Table 2.3 demonstrates that with two or more of the risk factors women are more at risk of cardiovascular events. The same is not true with only one risk factor where men have a higher chance of cardiovascular events. With no risk factors, the women are substantially more at risk in earlier ages than men.

Table 2.3 Combined cardiovascular risk

	Male risk factors			**Female risk factors**		
Ages	**No factors**	**1 factor**	**2+ factors**	**No factors**	**1 factor**	**2+ factors**
65-74	38%	47%	15%	48%	37%	15%
75+	37%	45%	18%	36%	40%	24%
Total	38%	46%	16%	43%	38%	19%

Adapted from (*Older New Zealanders - 65 and beyond*, 2004)

When looking at the numbers of men going into residential care compared to women in New Zealand, it appears that in relation to the total numbers of men both in residential care and those in the community, the proportion at 3 percent is smaller than that of the women at 8 percent. Only at age 65 does the percentage of men in residential care outnumber the percentage of women in residential care, but this is only by less than 1 percent. The actual numbers of men aged 65 and over, both in residential care and in the population in general, are less than that of women aged 65 and over (*Residential homes and hospital*, n.d.).

2.11: Activities of daily living

There are three different Activities of Daily Living (ADL) tests discussed in the literature as risks for residential care entry, and they are:

(i) Basic ADL, which measures activities such as bathing, dressing, transferring from bed to chair, toileting and walking;

(ii) Household ADL measuring household functions such as meal preparation, shopping and housework; and

(iii) Instrumental ADL (IADL) measures use of money, telephone and eating.

Neither ADL nor poor mobility were seen as predictors of residential care entry in a study involving over 1,000 participants (Black et al., 1999). However, an earlier study found that when ADLs were combined with lower body function that this increased the risk of residential care entry (Wolinsky et al., 1993). This 1993 US study was intentionally skewed to include more African American people, and oldest of the old, which might have affected the outcome when comparing it with Black's 1999 study. By far the majority of articles were in favour of the IADL impairments being one of the major contributor to residential care entry (Friedman et al., 2005; Greene & Ondrich, 1990). However the predictors of residential care may well be different for the frail older population already at high risk of residential care entry, from that of the general older population. Within a group of frail older people, it may well be the frailty (Bauer, 1996), and not the support network as suggested by others (Tsuji, Whalen, & Finucane, 1995), which is the predictive factor.

Excessive alcohol intake can affect an older person with mobility and ADL problems, which in turn can lead to falls and subsequent residential care admissions. It has been demonstrated in one Christchurch (NZ) study that 20 percent of older people in the study who lived in rest homes had lifetime alcohol dependence. Within the same group 5.1 percent continued to drink alcohol to such an extent as to put them at risk of further damage physically or mentally. The study then compared the alcohol levels between the older people in the rest homes and older people in the community, and found that 4.1 percent of older people in the community also had hazardous drinking patterns (Khan, Wilkinson, Sellman, & Graham, 2001). A later study found an even higher hazardous drinking prevalence of 9.9 percent among older community dwelling people in Christchurch (Khan, Davis, Wilkinson, Sellman, & Graham, 2002).

2.12: Hospitalisation

Prior hospitalisation has been found to be the most important predictor of residential care entry, combined with the willingness of the caregiver to admit to residential care (Bebbington et al., 2001; Miller & Weissert, 2000; Shyu & Lee, 2002) (UK). In Britain 43 percent entered residential care (providing lower level support) and 63 percent entered nursing homes (providing higher level support) after a hospitalisation (Dwyer, 2005) (UK). The health problem which had the older person admitted to hospital could have resulted in their becoming more dependent while in hospital (Cheek, Ballantyne, & Tucker, 1999) (Australia). If the older people had not been hospitalised, but been managed at home for the acute condition, the percentages of residential admissions may not have been as high. The hospitalisation itself could cause increased dependence because of the unfamiliar surroundings, for example the older person not knowing where the toilet was situated. On the other hand the older person could be disoriented and thus unable to find the toilet because of the acute illness.

The push for residential care may also be coming from hospital staff judging the older person purely in unfamiliar surroundings (Cheek et al., 1999). Nursing staff from busy wards may perceive the residential care option as less complex than discharging back to their own homes and arranging all the support services. If the older person is discharged from hospital to residential care, there would be no staffing worries about discharging in the afternoon, or prior to a weekend (Morgan et al., 1997) (UK). Some older people had thought about residential care prior to acute hospital admission, but hospitalisation acted as the catalyst for the move to 24-hour care. Acute health events, such as fractures and strokes regardless of their hospitalisation, have been cited by many as precursors for admission into residential care (McLean, 2003; Nolan et al., 1996; Russell et al., 1997; Ryan, 2000), but some feel it is merely the support worker's inability to cope (Devroey et al., 2002; Lundh et al., 2000).

2.13: Dementia

Thirty-four percent of the people with dementia in England live in residential care; however the majority of the residential care population (62%) have dementia (Matthews & Dening, 2002). Within New Zealand nearly 50 percent of people with dementia are living in residential care. The overall prevalence of dementia among older people within New Zealand is around 8 percent (*Dementia in New Zealand*, 2002). In a study of participants with dementia, it was found that no patient demographic, co-morbidity severity, or support worker characteristics significantly predicted residential care entry for this group (Fisher & Lieberman, 1999) (USA). Of the institutionalised people studied in Belgium (N=346) 30 percent had dementia, and 40 percent had motor function impairments as pre-existing conditions, with 54 percent living alone (Devroey et al., 2002) (Belgium). It appears that no studies link dementia categorically with residential care entry, but that it depends on the severity or attributes such as wandering and the ability of the caregiver are more predictive of residential care entry.

Depression has also been linked to residential care entry, (Lichtenberg et al., 2003) (USA). However, it could be argued that in all cases it is a combination, rather than one individual factor, which predetermines the likelihood of residential care entry.

2.14: Enabling factors

It is relevant to examine the factors influencing residential care entry in two of the three subdivisions most commonly described in the literature; that of enabling factors (influences which have an effect on the older person) and need factors (conditions which affect the older person). Highest on the list of enabling factors for residential care entry is the caregiving situation, the availability of the informal caregivers and formal support workers (Black et al., 1999; Miller & Weissert,

2000) (USA). To demonstrate this, older people with a neurological condition and with no relative nearby were 15 times more likely to enter residential care than those with the same condition who had relatives living nearby (Jette, Branch, Sleeper, Feldman, & Sullivan, 1992) (USA). The need for close family as caregivers is well illustrated in the studies about small-town New Zealand (Keeling, 1999, 2001).

There is an interesting relationship between availability of residential care beds and doctor's visits. If the doctor visits more often, the chances of residential care entry diminish, but if the availability of the residential care beds increase so does the chances of entry. Each physician visit over the preceding two months decreased the likelihood of entry by 5.6 percent. For every bed increase per thousand people over the age of 65, the likelihood of admission rises 0.7 percent (Greene & Ondrich, 1990; Tomiak et al., 2000) (USA).

Several studies have mentioned being poor, or receiving income support, as indicative of residential care entry, but only in conjunction with other factors such as age (Bebbington et al., 2001; Jette et al., 1992) (UK). One longitudinal study where the financial adequacy was measured at the commencement of the study (which could have been years prior to residential care, as opposed to cross-sectional studies where it was measured after residential care) found the reverse, that people who were financially disadvantaged had a lower chance of residential care entry (Palmore, 1976) (USA). Perhaps a person's money depletes while living in residential care to such an extent that they could be considered financially poor.

2.15: Need factors

The most commonly mentioned need factor is physical impairment, particularly the inability to perform essential ADL functions combined with poor lower body strength. It is the severity of the co-morbid diseases leading to difficulties managing in the home and the loss of coping skills which encourage residential care admissions, (Jorg, Boeije, Huijsman, de Weert, & Schrijvers, 2002; Shyu & Lee, 2002) (Netherlands) and a willingness by the older person to enter residential care (Mattimore et al., 1997) (USA).

Other factors less often mentioned as factors for residential care entry are poor knowledge of the community support provided, thinly populated non-metropolitan areas, and poor quality of life. (Black et al., 1999; Fisher & Lieberman, 1999; Nolan & Dellasega, 2000; Ryan, 2000) (UK & USA). Poor housing, security fears, environment problems (Dwyer et al., 2000; Howden-Chapman, Signal, & Crane, 1999; Jorg et al., 2002; Mattimore et al., 1997) (NZ & USA) and demographics such as poor education are also listed as factors leading to residential placement (MacNeill, 2000; Mattimore et al., 1997; Spillman & Lubitz, 2002) (USA).

2.16: Part 2 summary

Age and loneliness, the major factors for residential care entry go hand-in-hand with a decreasing ability to cope. This is compounded by so many older people with few friends or family in close proximity. There has been much discussion regarding ageism, such as structured dependence and disengagement theory, but a kinder view is the diversity of experience that the older person brings. Many people have commented that few people who are not of European descent entered residential care, which could be due to the smaller number of non-European descent people reaching older age, or that the residential care facilities are not culturally appropriate. A combination of factors is most likely to be the cause of residential care entry, rather than one specific reason.

Part 3: Decision-making for older people

The golden rule is that there are no golden rules

George Bernard Shaw, (1856-1950)

The review of the literature in Part 3 discusses who made the final decision for the older person to enter residential care, and the influences which might have been placed on the older person. Decision-making is paramount in the location or relocation of the older person. Firstly there has to be a valid choice, and secondly a decision-maker, then a decision. When the decision-maker knows about the subject matter, and the options (and if there is a possibility to change one’s mind), the decision-making seems to be less difficult (Popejoy, 2005) (USA). The decision-maker has the control over the final outcome of the placement, whether it is in residential care or for the older person to remain in their own homes. When the decision is made the level of satisfaction of both the older person and the caregiver needs to be assessed to ensure the most appropriate decision was made.

2.17: The choices for older person

Choice is one of the critical elements in the process of an older person relocating, as well as their ability to maintain an element of control, so that they perceive the move as voluntary and desirable, or at least legitimate (Davidson & O'Connor, 1990; Nolan et al., 1996) (Canada & UK). How preferences are influenced by the set of alternatives proposed is the key to understanding choice. Two principles are proposed by Simonson (1992); that of trade off contrast, and extremeness aversion. Consider the trade-off of a person’s own home and residential care. The trade-off principle would be the choice between the two with the tendency to prefer the quality (of life) of one over the other. The other principle, extremeness aversion looks at the disadvantages or advantages of one over the other; however it is assumed that disadvantages loom larger than the respective advantages when making this decision (Simonson & Tversky, 1992; Tversky & Kahneman, 1981) (USA).

To stay in their own home, Thorson argues, is preferable for most people because of the psychological and social familiarity of the home (Thorson, 2000) (USA), but Mattimore found that a total of 26 percent of older people were either 'very willing' or 'somewhat willing' to move to residential care (Mattimore et al., 1997). Oldman also stated that residential care was the choice of some older people (Oldman & Quilgars, 1999) (UK). There are only two real choices; firstly living at home with or without relatives, which can of course include being in a retirement village with serviced apartments or individual villas. Secondly, there is the choice of living in residential care. The contrast is living 'at' home as compared with living 'in a' home. Another choice, that of 'sheltered housing', has been developed in some countries, although only minimally in New Zealand, but there is a divergence of opinion between whether sheltered housing is 'institutional care' or 'home living'.

Even today there is very little consumer choice where the people are permitted to choose which community services they would like. Warnes in 1989 described a lack of choice, but this has not changed over the next 15 years. There is an inadequate range of services to provide for the level of services that are required to fit the older person's needs. Need is not defined in terms of preference or taste, but rather in terms of disability. The scarcity of resources may have some bearing on the paternalistic support which prevails, rather than a belief that there shouldn't be freedom of choice (Warnes, 1989) (UK). The choice of residential care facility can also be very limited, depending on the availability of rooms within the desired location (Sales et al., 2005) (USA). Despite the need-led rhetoric of 'Ageing-in-place' leading to choice for the older person, what is termed 'need' by the service providers District Health Boards (DHB) thus hinges on monetary resources rather than the difficulties experienced by the older person and the service users. In Britain a number of studies have shown that it is only the older people who are at very high risk and who would otherwise be unable to remain at home who are qualifying for assistance (Tanner, 2003) (UK); the same appears true, for New Zealand.

The residency choice is dominated by the paradigm of structured dependency:

> *which depicts residential care as exemplar of institution, and home as embodying personal control and self-identity* (Oldman & Quilgars, 1999, p. 363)

The concept of ‘batch living’ in residential care is contrasted by ‘public /private space’ and the ‘strangeness of people /the familiarity of people’. Residential care has been said to play a major role in ensuring the dependence status of older people in society, along with retirement and age related income (Townsend, 1981) (UK). Today’s institutions, such as residential care have been created from the framework of the harsh and punitive poor houses of the 1830-1880s (Bond et al., 1993) (UK). Conversely, poor health and immobility, the process of assessment and subsequent support delivery from bureaucratic organisations, can ‘institutionalise’ an older person in their own home setting without choice, just as easily as in residential care (Oldman & Quilgars, 1999) (UK).

2.18: The decision surrounding the placement of an older person

“*You can’t stay at home any longer.*” These and other similar statements are made to older people who need 24-hour support, but are unable to continue to live in their own homes in the community. It is a distinct possibility for many older people that they will experience a long-stay facility at some stage in their life. Few would choose residential care, but many acknowledge the possibility of such an event (McAuley & Travis, 1997) (USA). From the relatives perspective it can be that there is nothing else they can do but put the older person in a ‘home’, or a final sign of failure. An ideal would be that the decision to relocate to residential care should be made out of desire rather than necessity, although this is rarely the case. The decision is at times forced on older people and families after an event such as admission to an acute hospital, when the older person is already dislocated from their usual and familiar surroundings. These times have been described by some families as ‘decisions in times of crisis’ (Bell, 1996; Lundh et al., 2000; Nolan et al., 1996) (UK). The difficulty of the decision is further exacerbated by the pressure on the acute hospital beds and the intimidation of the whole process (Davies & Nolan, 2003; Ryan, 2000) (UK).

How the decision is made, or not made by the older person, interacts with how the choices are presented and the particular personality of the older person. There are many papers written about decision-making especially with reference to the end-of-life choices and the use of family members, spouse, or children as surrogate decision-makers (Pratt, Jones-Aust, & Pennington, 1993; Roberto, 1999) (USA). However, that decision is somewhat different in context to that of choosing where the older person will reside for the rest of their lives. Framing of the decision (problem) can have predictable shifts of outcomes when the same problem is framed in different ways. The preference of the person assisting the older person, or giving the options to the older person, is of significant concern for rational choice. The outcomes are usually perceived as positive or negative, rather than neutral, when presented to the older person, which can also have a significant bearing on the outcome (Tversky & Kahneman, 1981) (USA). The most obvious principle is dominance, where one option is better than another in one area, and at least as good in all other areas, thus leading to the dominant option being chosen (Tversky & Kahneman, 1986). The strategies used by the caregiving daughter which most frequently influenced the older person, were positive, with negative and option-seeking strategies being used less often (Pratt et al., 1993) (USA).

There are two hypotheses when looking at consumer choice, which is the choice being made by the older person for accommodation. First is the trade-off contrast, which extends the notion of contrast to the comparison of trade-offs, where a poorer option increases the desirability of the superior option, or enhancement and detraction. The second hypothesis is the extreme aversion which derives from the thoughts that disadvantages are more noticeable than the respective advantages, leading to the notion of loss aversion. This leads to the compromise effect where the addition of the extreme option increases the likelihood of the middle option being chosen rather than the extremes (Kelman, Rottenstreich, & Tversky, 1996; Simonson & Tversky, 1992) (USA). No matter who presents the problem to the older person, the decision-making appears to be less difficult when the decision-maker knows all the relevant facts and is aware of the outside forces that influence the decision. These include the perception of the older person's safety, the different options available, and the power relationships present among the decision-makers (Popejoy, 2005) (USA).

When decision-making was examined, the results showed that only 20 percent of the group of older people chose to participate actively in decision-making, with the rest choosing a collaborative or passive role. The findings also showed that the health system showed a paternalistic approach to older people (Doherty & Doherty, 2005) (UK). This leaves a huge responsibility to those advisors of older people to 'get it right' as far as accommodation for those needing high and very high levels of support. Potential barriers for the older person, such as lack of information and limited staff time, have also been described as making it difficult for older people to exercise their right to self-determination (Doherty & Doherty, 2005). Another problem identified for the older person at the time of decision-making is the lack of planning prior to the event. Also family influence, particularly the women, on the residential care placement decision appeared to follow a hierarchical pattern with the older person rarely influential in the process and health care professionals pre-eminent in the role (Bell, 1996; Edwards, Courtney, & Spencer, 2003; McAuley & Travis, 1997) (USA).

There is a diversity of opinions regarding the frequency of hospital admission prior to residential care entry, with Lundh (2000) finding the majority of older people made the decision due to a growing awareness of the inability of the caring role to continue (Lundh et al., 2000) (Sweden). Most of the researchers agree, that the majority of older people were hospitalised prior to residential care entry (Devroey et al., 2002) (Belgium). Several factors were found to influence the decision for an older person in Australia to enter an acute care service. Some of these factors are similar to those noted for admission to residential care facilities. They were that their support networks had fallen down and there were no safety nets or after hours support (Cheek, Ballantyne, & Roder-Allen, 2005) (Australia).

Several factors can both enhance the decision to admit the older person to residential care, such as, incontinence especially bowel (Osterweil, Martin, & Syndulko, 1995; Tsuji et al., 1995) (USA), wandering behaviour (G. E. Smith, O'Brien, Ivnik, Kokmen, & Tangalos, 2001; Yaffe et al., 2002) (USA), and inadequate support worker resources. Detracting from the decision are thoughts such as living apart from one's family members (Davies & Nolan, 2003) (UK). Another little-discussed decision is that of being sent home from the acute hospital, from the perception of the older person and the family's wishes.

2.19: Control over one's life

Perceived control over the decision to either enter residential care or not is usually beneficial, unless of course the new environment is unpleasant (Davidson & O'Connor, 1990) (Canada). Allowing the opportunity of participating in autonomous decisions, such as relocation, allows the older person control over their health and survival, and is an essential part of quality support (Lambert et al., 2005) (Canada). For an older person Nolan (1996) has coined three major roles in the continuum of control: (i) The 'isolate', who maintains all control and makes the decisions autocratically, either because there was no one else or as a matter of choice;

(ii) the 'partner' with either senior, equal or junior control with another person or persons who could be a spouse or family; and (iii) the 'outsider' where the control is completely taken away from the older person with little or no consultation with the older person (Nolan et al., 1996) (UK).

Even when very old it is still important to feel that sense of control, to prevent the damaging effects of relocation on morbidity and mortality (Rodin, 1989) (USA). However, it is more frequently found that older people are expected to have, and frequently found to have, much less control than younger people, (Wolinsky & Stump, 1996; Wolinsky, Wyrwich, Babu, Kroenke, & Tierney, 2003) (UK), perhaps because of spousal loss or retirement.

The person or persons with control are the ultimate decision-makers of where the older person will live. How much do older people understand, or just accept, when a health professional suggests residential care entry? Decision-making means influence and control, which includes knowing the options available. Doctors are assumed to have formal control and social power, which, particularly for older people, is a deterrent to questioning (Gallois & Callan, 1997) (UK). Even competent older people, when unwell and hospitalised, often have difficulty with decisions, so communication becomes even more important to ensure older people understand their options (Crane, 1997; Fuller, Dudley, & Blacktop, 2001) (USA).

As a consequence of time constraints and communication problems relating to the use of medical jargon and older peoples' ability to communicate, (Beck, Daughtridge, & Sloane, 2002; Tierney et al., 2001) (USA) staff may not necessarily take the time to ensure that older people understand the implications of decisions. Even with good communication, decision-making is a complex subject with vast differences apparent amongst different population groups (Cleary & Edgman-Levitan, 1997; Thomas & Thomas, 1994) (USA & NZ). While the decision regarding residential care placement is usually unplanned (H. Barnes & Parry, 2004; Cheek et al., 1999) (UK) and not usually a result of a deliberate choice by the older person involved, it appears that the crux of the whole decision-making process is the quality of communication, understanding, and who is perceived to have control (Nay, 1995; Nolan & Dellasega, 2000) (UK).

Primary influence over decision-making is said to be generally held by three groups of people: the health professionals (Cheek et al., 1999; Nolan et al., 1996; Sandberg et al., 2001) (Australia & UK) the family (Davies & Nolan, 2003; Nolan & Dellasega, 2000; Shyu & Lee, 2002) (UK); and to a much lesser extent, the older person (Mattimore et al., 1997; Nay, 1995; Wilkinson & Sainsbury, 1992) (USA). It is perceived that typically people other than the older person initiate the move into residential care (S. Dwyer, 2005) (UK). This is demonstrated or explained by a study of 48 people in Britain (2003) which concluded most of the people were considered too cognitively impaired to participate in the decision making (Davies & Nolan, 2003) (UK). However, the diagnosis alone does not necessarily mean that the older person cannot make a residence decision for themselves. Because the decision to remain at home requires a sense of personal control and self–motivation, most older people go along with the decisions of others to move into residential care when it is suggested (Miller & Weissert, 2000) (USA).

It is often also perceived by the older person that it is the doctor who told them they should enter residential care, leaving the decision as ‘expert-driven’. In a comparison between decision-makers in the UK and USA it was found that general practitioners were involved in the majority of residential care placements (UK 73% and USA 59%). Hospital doctors were involved in half the placements in both countries, but social workers were much more likely to make decisions in the UK (63 percent) than in the USA (28 percent). Only one older person out of 10 in the USA and one person out of seven in the UK exercised a positive choice to enter residential care (McAuley, Travis, & Safewright, 1997; Nolan & Dellasega, 2000) (USA). A study of 9,105 patients concluded that:

> *patients* [older people] *were often unable to participate in the decision when long-term care choices needed to be made, leaving surrogate decision-makers, guided by the patient’s physician to decide whether patients will be placed in nursing homes* (Mattimore et al., 1997, p. 819)

What is worrying is that the surrogates correctly answered the older person’s wish only 61 percent of the time (Mattimore et al., 1997) (USA). Few older people felt that they had a real choice, so they lost the sense of future that one gets when one relocates from house to house, or town to town (Nay, 1995) (UK). Health professionals are seen as ‘deciders’ either working independently or as part of a multidisciplinary team (geriatricians, general practitioners, registered nurses, physiotherapists, occupational therapists or social workers). They make decisions and recommendations after an event, around the time that the older person is discharged from hospital (Cheek et al., 1999; Davies & Nolan, 2003; Nay, 1995; Nolan et al., 1996) (UK). Family in some cases also play a major part and take up the role of deciders for the older person.

> *Support workers may have considered nursing home care as an option*,[but] *they have rarely discussed such a possibility with the cared-for person* (Dellasega & Nolan, 1997, p. 446)

Some caregivers express the difficulties with lack of information and both the older person and the caregivers complain about the 'medical speak' of the doctors. The caregiver and older person frequently have only been given a list of 'homes' to choose from. Others who help the family with the decisions would include the person with the power of attorney, neighbours and close friends (Davies & Nolan, 2003; Gibler, 1998; Hagen, 2001; Keeling, 1999). Older people in general are less likely to make the decisions (Minichiello, 1987) (Australia), but some can take control of their lives and decisions, and not only make the decisions but understand that they have made that decision (Mattimore et al., 1997; Nay, 1995; Wilkinson & Sainsbury, 1992) (USA &UK). This, however, is rare (Nolan & Dellasega, 2000) (UK). Interestingly, out of 4,301 older people, 7 percent said they would be 'very willing' to live in residential care and 19 percent said they would be 'somewhat willing', which would seem to indicate that some older people, albeit a small percentage, are happy with the move to residential care (Mattimore et al., 1997) (USA).

2.20: Satisfaction with the final placement

Satisfaction can be gauged in many different ways, such as illustrated in the study looking at possessions, which found that for elderly women possessions played an important role in their satisfaction (Cram & Paton, 1993) (NZ). The ability of people to take their personal possessions to residential accommodation has always been a dilemma from the point of space in the institution. While older people are often reported as being more satisfied with life, those with greater functional impairment and a poorer self-perceived health reported lower satisfaction, similar to older people who were having support worker problems (Bearon, 1989; Chesterman, Bauld, & Judge, 2001) (USA). Older people often adopt the approach of passive acceptance in order to deal with the less favoured aspects of communal living, such as eating with others, while others say they conform and make the best of it (Lee et al., 2002) (China).

Satisfaction for the older person has been researched from many different angles. One paper compared satisfaction to personal goals (Rapkin & Fischer, 1992) (USA). Others pointed out the major significance for satisfaction of the following: health (to older women), the centrality of family, maintaining the status quo, and preventing fears from being realized (Baltes & Mayer, 1999; Bearon, 1989; Lapierre, Bouffard, & Bastin, 1992) (USA). It has also been found that there was no difference in life satisfaction between the age groups ranging from 45 to 75 years and people over that age (Hamarat et al., 2002) (USA) although this differs from the statements that satisfaction increased with age, which has been well researched by others (Cheng, 2004; Herzog & Rodgers, 1981; Herzog & Rogers, 1988) (USA). Satisfaction did vary slightly between countries, thus in the United Kingdom for example the older person reported the need for good health (which included independence and mobility), emotionally satisfying ties (Baltes & Mayer, 1999) and being personally clean and socially integrated (Netten et al., 2002) (UK). The American sense of well-being consisted of being in control, a sense of purpose, and having an absence of negative feelings (Plaut, Markus, & Lachman, 2002) (USA).

Men and women differ in their life satisfaction. For men personal functioning, control and income appear to influence life satisfaction, while for women social integration is important. These factors have a direct bearing on any proposed move into residential care especially for women (Bourque, Pushkar, Bonneville, & Beland, 2005) (Canada).

2.21: Part 3 summary

The literature review demonstrated that both increasing age and the older person's difficulties with daily functions were significant risk factors for residential care entry. Figure 2.2 illustrates the ten most commonly mentioned risk factors.

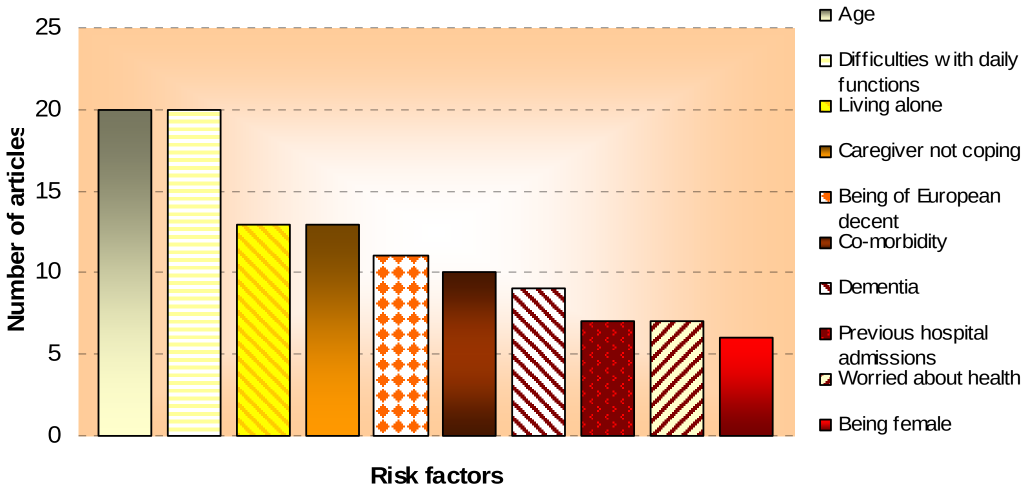

Figure 2.2: Risk factors cited in the literature

After an older person has been assessed as needing a level of support consistent with residential care entry, a decision may need to be made about the eventual residence for that person. Decision-making surrounding residence encompasses influence and control, but to be able to make a decision, the options available must be apparent. The competent older person, when unwell (and hospitalised) has difficulty with decisions, so good communication, which has been demonstrated as being an important part of patient discharge, becomes essential (Crane, 1997; Fuller et al., 2001) (USA). As a consequence of time constraints and communication problems relating to the use of medical jargon and the older person's ability to communicate (Beck et al., 2002; Tierney et al., 2001) (USA), staff may not take the time to ensure the older person understands the implications of the decisions. Also doctors are assumed to have formal control and social power, which particularly for the older person is a deterrent to questioning (Gallois & Callan, 1997) (UK).

Even with good communication, decision-making is a complex subject with vast differences apparent amongst population groups (Cleary & Edgman-Levitan, 1997; Thomas & Thomas, 1994) (USA & NZ). While the decision regarding residential care placement is usually unplanned (Barnes & Parry, 2004; Cheek et al., 1999) (UK) and not usually a result of a deliberate choice by the older person involved, it appears that the crux of the whole decision-making process is the quality of communication, understanding, and who is perceived to have control (Nay, 1995; Nolan & Dellasega, 2000) (UK). The literature points out that primary influence over decision-making is generally held by three groups of people: (i) the health professionals most often (Cheek et al., 1999; Nolan et al., 1996; Sandberg et al., 2001) (Australia & UK); next (ii) the family (Davies & Nolan, 2003; Nolan & Dellasega, 2000; Shyu & Lee, 2002) (UK); and lastly to a much lesser extent (iii) the older person (Mattimore et al., 1997; Nay, 1995; Wilkinson & Sainsbury, 1992) (USA).

The older person's satisfaction with the decision of where they would live was also difficult to research in articles. Two articles which were somewhat related to the topic gave varying perceptions of the relationship of personal satisfaction to age. One article said satisfaction increased with age, while the other stated that age made no difference to satisfaction (Hamarat et al., 2002; Herzog & Rodgers, 1981) (USA). As one of the ways of eliciting the amount of the older person's satisfaction with the residence decision, it was decided to investigate what, if anything, the older person would like to change. Literature on older peoples' wishes for change was not prevalent, but better health, social integration and being in control were the most prominent 'wishes' in the articles which could perhaps relate to this.

The major decision to relocate to residential care is often not made by the older person, but by a surrogate decision-maker, such as a female family member. Physicians are often very influential, especially if there has been a prior hospitalisation, but medical jargon is a barrier to the older person's participation. Most of the older people appear to be resigned to the fact that at some stage in their life they may need to be in residential care, although this is not a good outcome from their perspective.

The effects of the population ageing, both worldwide and within New Zealand, will undoubtedly have an effect on all the key stakeholders within the ageing sector. The decreased birth rates in the developed countries lend credence to the proposed ageing population scenario, without even considering the decreased mortality of the older people. The effects of the Baby Boomer population reaching aged 65 from 2011 to 2030 will also cause a dramatic increasing in the sector. It is evident that lifestyles have changed significantly since 1900 which has impacted upon the family structures and expected duties. Lifestyles and financial implications have also influenced the support of the older person, which leaves little time or money to assist in supporting them. In line with the World Health Organisation the New Zealand Government has implemented policies which will lead towards enabling more older people to 'age-in-place', by supporting developments like healthy living and rehabilitation.

Residential care has changed from the days of the 19th century, when it was more or less punitive for poor older people who needed support to be incarcerated in the state run 'poor houses'. Now in the 21st century, retirement villages, which include residential care, are becoming big profitable businesses. Although most older people live in their own homes, this becomes more difficult when they live alone. As a person ages they become more withdrawn from society, either because society withdraws from them or they withdraw from their obligations and friends within society. When a person reaches the level of dependence there is always the question of residential care or support at home. This becomes dependent on many factors including the availability of informal support from family or friends, and/or formal support from the DHBs.

The question of who makes the decision to seek residential care is important. It raises many ethical questions centred around how much authority the older person has. The literature would seem to suggest that the older person is often a minor participant regarding their future placement either at home or in residential care. Most of the older people in the studies felt that it was the health professionals, in particular the doctors, who had made the decision, but it was also apparent that the families in many cases did have their say in influencing the older person.

Most of the predisposing factors surrounding residential care entry are combined with others, so it is difficult to state categorically which ones are definite indicators of residential care placement. With almost all of the factors there was a counter argument which illustrated there were very divided opinions regarding this subject. Some predisposing factors were consistently mentioned, such as age, living alone and ethnicity. Most of the articles agreed that females were more predisposed to enter residential care than males. However there was the argument that men were not as healthy and therefore would have a higher risk than women in some countries.

Although most of the older people entering residential care usually had an acute hospital visit at some time prior to residential care entry, this was not seen as indicative of future residential care. However, the push for shorter acute hospital stays may well lead to earlier discharges, when the older person is still highly dependent and therefore unable to return to the home environment. It is also much faster, easier, and presumed safer, for the hospital staff to discharge to residential care where things are ‘set up’, rather than having to discharge home where appropriate support structures may have to be initiated to allow for safe housing of the older person. There was discussion surrounding the residential care of older people with dementia where some advocated that this was a predisposition for residential care entry and others discussed the issue as being totally support worker related. The majority seemed to agree that when the older person became very disoriented and at a stage where safety was an issue, then placement in residential care was mandatory. Support was discussed as one of the enabling factors which either assisted the older person to enter residential care or assisted them to remain at home. The availability and closeness of family was the enabler which allowed the older person to remain at home, whether with their family or in their own homes.

The review has shown that for almost every factor which could be a risk for residential care entry, there is another way of looking at it and an argument against it. The conclusion would appear to be that it is not one factor alone which could predict entry, but a combination of many co-morbid conditions, age, and also the motivation of the older person and family availability.

Chapter 3

ASPIRE

> *Discovery consists of seeing what everybody has seen, and thinking what nobody has thought* Albert von Szent-Györgyi (1893-1986)

OPERA (Older People Entering Residential Accommodation) was a sub-study of the ASPIRE (Assessment of Services Promoting Independence and Recovery in Elders) trial. ASPIRE was a randomised controlled trial to evaluate the effectiveness of Ageing-in-place initiatives (AIPI). OPERA was developed to investigate areas not addressed by ASPIRE, specifically the areas relating to residential care entry such as the decision-making and the older person's satisfaction with the decision, and the factors which could influence entry.

In 2002, the New Zealand Health of Older People Strategy was developed by the Ministry of Health (MoH) to provide services which allowed older people to age in place (remaining at home rather than in institutions). The older people specifically targeted were those who were categorised as needing the level of support consistent with entry into residential care (rest homes, or continuing care hospitals). Objective 8 of the Older People Strategy states that:

> *Older people with high or complex health and disability support needs will have access to flexible, timely and co-ordinated services and living options that take account of family and whanau carer needs* (Ministry of Health, 2002b, p. 57)

Prior to 2002 the residence options for people needing high levels of support were few. Residential care was the only option if the older person had lost their main support person, or the support services needed were more than could be provided by the public health services and their support person. Figure 3.1 demonstrates the support options available (living in the community to 24-hour care) for the older person with increasing support needs.

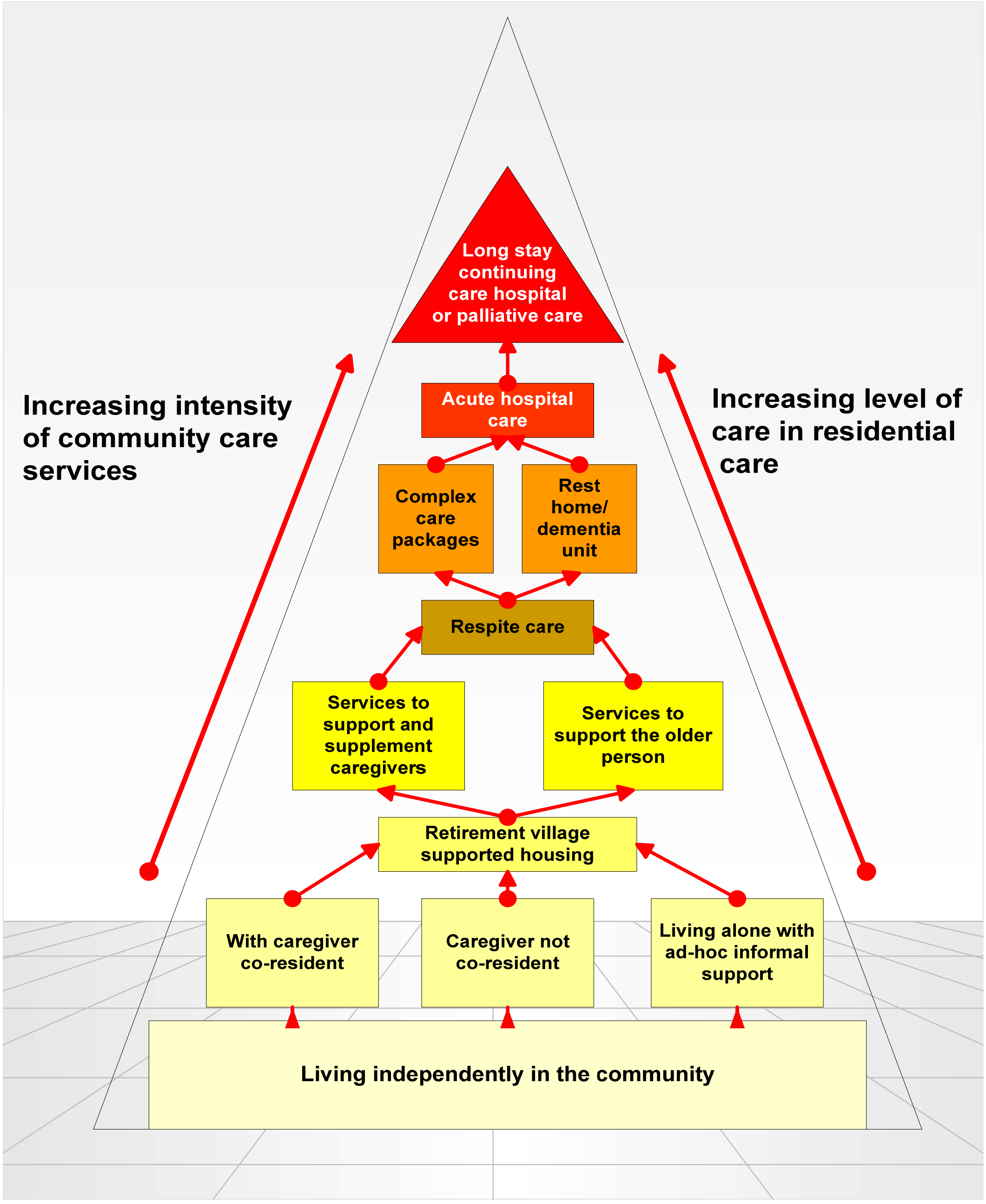

Figure 3.1 Support options for different levels of need Adapted from (Ministry of Health, 2001a)

Due to the lower birth rates and the influx of people born between 1945 and 1965 (Baby Boomers), and higher life expectancies, people over the age of 65 will make up one quarter of the population by 2051 (Pink, 2001). The reasons for this increase in the ageing population differ for the developing and developed countries. In developed countries population is driven by reduced death rates for older people, while in the developing countries it is largely the consequence of preventing childhood diseases. Life expectancy increases ranging from 4.1 years to 13.1 years (in sub Saharan Africa) are expected by the year 2020 (Bonita, 1997).

Social networks are a very important content of Ageing-in-place, although the general trends are of a shrinking social network as one ages (Keeling, 2001), with the older person becoming increasingly neighbourhood-based and often neighbourhood-bound (Cantor, 1975). The informal support systems provided a substantial amount of support, without which the older person may well have been forced to enter residential care (Branch & Jette, 1983; Cantor, 1983). The changing demographics with the older population have increased the necessity to have proven Ageing-in-place strategies in New Zealand, as well as other developed countries.

The Ministry of Social Policy (MSP) and the MoH worked together on a project which supported older people and enabled them to have a real choice of where they lived. The Positive Ageing Strategy (PAS) described freedom of choice by developing a workforce for the delivery of improved services within the community. A document, written for the Minister of Senior Citizens states that one of the four main areas for planning and action will be:

> *Developing a specialised workforce in older people's health with a greater emphasis on skills needed to work with older people and their families, whanau and caregivers in community and home settings* (The New Zealand positive ageing strategy, 2001, p 40)

The PAS policies ensured that the health needs of older people were met, both in institutional and community environments. The first policy discussed living choices for the older person. To achieve this outcome, the MoH sought to evaluate initiatives which provided alternative options to residential care. Several different initiatives were developed throughout New Zealand, in conjunction with the MoH, and later the local District Health Boards (DHB). These initiatives were alternatives to the present models of support provided by either the residential care facilities or the existing home services. Existing home based services were brokered for the older person by the Needs Assessment Service Co-ordination (NASC) service, which was funded by the DHB.

3.1: Ageing-in-place initiatives

Three AIPI were developed to target older people who were categorised as needing a support level consistent with residential care entry. The AIPIs provided older people with alternative support to enable them to remain within their own homes if they wished to. Separation of the type of support from the place of residence was one of the more important concepts of Ageing-in-place. This separation enabled support to be provided which was tailored to the specific needs of the older person. The changing needs of the older person were monitored by regular assessment by members of the AIPI, which allowed changes to the support services given. For the AIPIs to work, the older person must have lived in a supportive environment where independence was encouraged.

A second important concept of the AIPIs was the appointment of a case manager. The case manager (a nurse, physiotherapist, social worker or other health professional) was assigned to administer and co-ordinate the health and community services provided to the older person. These home services included identifying barriers (such as a lack of some important equipment), and the provision of direct support. Case management was normalisation, choice, accessibility and advocacy (on the part of the professionals), and flexibility and innovation (on the part of service management) (Bergen, 1992, 1994, 2003). Case management was a method of co-ordinating three areas of service to meet the needs of the individual within the community, namely: (i) social entrepreneurship (an agency where the budget was held to purchase packages of support); (ii) service brokerage (a case manager acting as an advocate for the older person, located outside of both funding and providing agencies); and (iii) key worker or co-ordinator (multidisciplinary teams providing support) (Bergen, 1992).

Studies comparing case management to existing services have shown that institutional-based support was deferred to community-based support, and the measurement of treatment intervention was more appropriately outcomes-based (Watt, 2001). Very few of the existing interventions for community dwelling older people took a preventative or rehabilitation approach (Hallberg & Kristensson, 2004). In discussing the situation with older people prior to case management, many thought they had lost control of their bodies and their destinies. Case management gave the older person more of the control (Nelson & Arnold-Powers, 2001).

Ageing-in-place initiatives differed from existing services, which were either non-existent, provided in the sterile clinical setting of a public hospital or similar clinic, or were infrequent home visits by a professional usually in an untimely manner. The specific areas of difference were in one or all of the following ways. It: (i) brokered the services themselves; (ii) provided the service in the place of choice for the older person, usually their own homes; (iii) tailored the services specifically for the older person and their home environment; (iv) provided one specific MDT member who was best suited and able to provide the service; (v) provided the ability to visit the older person many times each day if required; (vi) taught the older person's own support person to enable them to continue with the programme on completion of the MDT services, and; (vii) provided a case manager (health professional) who administered and co-ordinated the service for up to one year.

The AIPI teams (which included medical and healthcare personnel) participating were: (i) The Presbyterian Support Northern (PSN) Community FIRST (Flexible Integrated Rehabilitation Support Team) service in Hamilton; (ii) Wellington Masonic Villages Trusts Promoting Independence Programme (PIP) in Lower Hutt; and (iii) The Co-ordinator of Services for Elderly (COSE) in Christchurch.

Community FIRST and Masonic PIP were essentially rehabilitation for the older person within their own homes. COSE differed by not providing rehabilitation, but brokering the support services. The similarities between the three models were that they all provided a case manager, looked at alternatives for residential care placement, and targeted those older people who had high or very high support needs.

Community FIRST

Community FIRST was a multidisciplinary team approach which provided restorative home-based services, with optional rehabilitation orientated residential care placement. This initiative supported the notion of Ageing-in-place for those older people who might otherwise be placed in residential care. Extensively trained support workers delivered goal-orientated rehabilitation packages with case management overseen by health professionals (nurse, physiotherapist, occupational therapist). The rehabilitation was based on repetitive Activities of Daily Living (ADL) exercises. The older person identified meaningful goals to work towards and achieve within the programme. Visits were up to three to four times a day, seven days a week if necessary.

Masonic PIP

PIP was a rehabilitation programme for people who had not maximised their potential upon discharge from hospital. A case manager was assigned to each person to initiate and co-ordinate the rehabilitation. The team consisted of registered nurses, occupational therapist, physiotherapists, speech therapist, social worker, podiatrist, dietician, kai awhina (Maori liaison person), and rehabilitation assistants. The PIP team provided rehabilitation and oversight for up to one year. Alongside the rehabilitation programme, the team undertook a comprehensive handover to the formal support workers and informal caregivers, which allowed for the individually tailored programme to continue.

COSE

The COSE worker, based within primary health, was a nurse, social worker or occupational therapist who was assigned to a cluster of designated general practitioner (GP) practices, but worked independently of the practices. The COSE worker, a case manager, liaised with the GPs and practice nurses. Older people were assessed by the COSE worker for their support needs to ensure that there was recognition of, and a quick response to, any change in the older person's circumstances. Close monitoring enabling the level of support required for safe continuous Ageing-in-place. The worker also co-ordinated the appropriate community services, informal networks and medical care based on the assessed need and GP liaison.

3.2: ASPIRE: a prospective meta-analysis

ASPIRE was a prospectively planned meta-analysis of Randomised Controlled Trials (meta-RCT), which involved the pooling of data of the three initiatives (AIPI), which used a common paradigm for managing the support of older people within the community. The ASPIRE hypothesis sought to test the AIPI improvement against conventional support, in survival and reduction of permanent admissions to residential care, physical function, independence, 'physical' and 'mental' health-related quality of life and social activities. ASPIRE also investigated the quality of life, mental well-being of the primary informal support worker, and the economical efficiency for the client, family, providers and funding agency. The longitudinal study assessed people up to five times, firstly at randomisation, then at intervals up to 18 months (3, 6, 12, and 18 months).

The sample population were older people aged 65 years or above (or 55 and over for Mäori) who were living in one of the three study sites. The participants were assessed as having ‘high or very high’ health and disability needs and living at home. The sample was randomised into control and intervention groups within each research site. The research design divided the areas according to: high or very high health needs; age below and above 74 and 75 years respectively; gender; and living situation (alone or with others). Each of the areas was randomised with equal probability of placement in the control or intervention groups. The total sample was 569 participants.

Recruitment strategies

Slightly different strategies were used for the three sites. Community FIRST, Hamilton and Masonic PIP, Lower Hutt, were the same, while the COSE, Christchurch, was structured differently. In the Hamilton and Lower Hutt groups, following NASC assessment of the older person’s support needs and confirmation of entry criteria, the older person was asked if they wished enter the trial and consent was gained. The referrals to the NASC came from the hospital Assessment Treatment and Rehabilitation (AT&R) wards, the medical wards, and the community. If the older people were found to have high or very high support needs, they were referred to the ASPIRE researcher for randomisation to the control group or AIP (FIRST or PIP), and an initial interview. The researcher then referred to the AIP those who were not randomised to the control group. Both groups of people had up to five interviews from the researcher.

The Christchurch group process commenced with referrals from the hospital or the community, where the people with high or very high support needs were randomised to either general practitioner groups with independent COSE case co-ordinators (1 to every 3000 older people living in the area), or to the general practitioner groups using the NASC co-ordinated services. The NASC group would be the control group. Both groups would also have at least five interviews.

3.3: OPERA as a sub-study of ASPIRE

OPERA was developed from the ASPIRE trial to investigate specific areas of residential care entry which were not addressed, such as the factors which influence the older person to enter residential care, and the decision-makers. OPERA also assessed the older person's satisfaction with the decision regarding where they would live (residential care or home). The participants for OPERA (N=131) were all drawn from the existing participants within the ASPIRE trial (N=569), except for the residential care participants of the OPERA pilot study (N=13). OPERA commenced data collection in November 2004, one year after the ASPIRE trial commenced, and concluded in December 2005. In January 2006 OPERA accessed the complete data set from ASPIRE for statistical analysis surrounding its specific research questions. During the collection of the OPERA data (one year) the researcher for the face-to-face interviews for the Lower Hutt ASPIRE and the face-to-face interviews for OPERA was the same person. The researchers for the collection of the data in Christchurch and Hamilton ASPIRE trials obtained the OPERA signed consent forms from the older people and caregivers, as well as the face-to-face interviews with the older people living in residential care.

3.4: Chapter summary

The ASPIRE trial examined the AIP initiatives in Christchurch, Lower Hutt and Hamilton with the view to providing more opportunities for older people to remain in their own homes. The research also identified which programmes provided the highest quality of life gains in comparison to expense. It considered if there were greater benefits for the older person when remaining in their own homes, rather than being permanently admitted to residential care. To enable this, three different kinds of services were trialled: Community FIRST, in Hamilton: Masonic PIP, in Lower Hutt: and COSE, in Christchurch. (At the time of writing the ASPIRE trial had nearly completed its data collection). OPERA developed as a sub-study of ASPIRE with the purpose of examining areas not covered by ASPIRE. These were to find out the factors surrounding residential care entry for older people assessed as needing high or very high levels of support, and the older person's satisfaction with that decision. Also investigated were the decision-makers for the older person when deciding where they would safely live.

Chapter 4

Methodological review

> *Scientific knowledge is constructed by the development of theories aimed at the integrative organisation of information and at the guided search for increased information* (Baltes, Reese, & Nesselroade, 1977, p 26)

This chapter will examine the particular types of research used within OPERA, namely mixed methods research and its different components. Included is a brief summary of both qualitative and quantitative research with comments regarding longitudinal and pilot studies. It is relevant here to also examine research on older people with respect to using both face-to-face and telephone interviews.

There are at least two aspects to any methodological review: firstly, the empirical method in general, which is the nature of the knowledge and the nature of the scientific method: secondly, the subject matter unique to the research (Baltes et al., 1977, p 14). The nature of this study and the broad scope of the data arising from it led to a mixed methods research approach being selected. Mixed methods research is the combination of two methods, quantitative and qualitative research. A qualitative approach was useful to draw the wide perspectives together to portray as many aspects as possible, while the quantitative approach led to statistical analyses of the data. Longitudinal methods gave a continuum over time.

Research with older people can have both positive and challenging aspects. Telephone interviews have proved a satisfactory manner of eliciting older people’s thoughts, especially if forewarned by a direct contact approach. Prior to starting any study, especially with older people, pilot studies are useful for gaining knowledge to help the development and discovery of impediments to the research, as well as being a feasibility test.

4.1: Mixed methods research

Mixed methods design collects both quantitative and qualitative data (Cresswell, 2003). The information can be gathered from questionnaires which include both closed and open-ended questions (Patton, 2002). This research method uses the data collection and analysis techniques in parallel, or sequential models in the methods section of the study (Tashakkori & Teddlie, 2003). The following quote illustrates the primary reason for the method:

> *One of the major reasons for following the fundamental principle of mixed methods research is to elucidate the divergent aspects of a phenomenon* (Tashakkori & Teddlie, 2003, p 17)

When compared with a single research method, which may be constrained by the method itself, mixed methods design allows for the research to develop as comprehensively and completely as possible. There are widely held views that because social phenomena are so complex, mixing different types of methods can strengthen a study (Tashakkori & Teddlie, 2003). Writers have stated that mixed methods studies are combinations of qualitative and quantitative paradigms, methods or techniques, but it is the distinctive execution and representation of the methods which signal the key differences in inquiry (Tashakkori & Teddlie, 2003).

The mixed methods approach is less well known than either qualitative or quantitative methods individually, but it enables multiple approaches to data collection (Cresswell, 2003). As a way of reducing biases within mixed methods, triangulation can be used for seeking convergence across both the qualitative and quantitative research methods. There are four types of triangulation:

(i) data triangulation, where as many different data sources as possible are analysed:

(ii) investigator triangulation where different people look at the same area:

(iii) theory triangulation where there are many different perspectives in relation to the same objects: and

(iv) methodological triangulation where different methods are used to address the same area (Corner, 1991).

When looking at mixed methods studies to judge if they are convincing, it is essential to investigate how well the needs and expectations of the readers representing the particular mix of interpretative communities have been met (Tashakkori & Teddlie, 2003). To understand the mixed methods design it is helpful to understand both parts which combine to form mixed methods research.

Qualitative research

Qualitative research seeks within a natural occurring setting to understand specific behaviours and their subtle variations, and uses categories to describe and analyse the social phenomena (Meadows, 2003; Pope, Ziebland, & Mays, 1999). A general inductive approach to qualitative research builds categories gradually from the extensive raw text data, and condenses it into a summary format (D. R. Thomas, 2003). The source of the raw data is from responses to open ended questions which then provide the quotations (Sewell, 2002). A major point of inductive theory is to avoid preconceptions from narrowing what is observed and theorised (Ezzy, 2002). With the qualitative design, interaction between older people can be used, such as focus groups, or conversely interaction between different individuals with the same primary focus. Audio tapes and/or notes of face-to-face or telephone interviews are transcribed often verbatim to provide very rich text, which can include comments on sighs, laughs, and reports of body language (Pope et al., 1999).

Qualitative research can also be a precursor to a quantitative study by generating research questions. This can be seen particularly in pilot studies. Trustworthiness, which includes consistency and credibility, is a term used to describe the accuracy of the qualitative research (D. R. Thomas, 2003). Reliability may be of little relevance if the unique situations can not be reconstructed. Consistency to measure the extent to which the account portrays the social phenomena accurately can be assessed by triangulation and inter-rater reliability of coding. This is tested by asking another researcher independently to code some of the raw data, and compare the coding. Another advantage of triangulation is that it can make the study more comprehensive, and encourage more reflective analysis of the data, as well as testing validation (Pope et al., 1999). Respondent validation or stakeholder checks ensure the credibility of the data collected, by checking its accuracy with those involved. Methods triangulation can also be used, and can occur when qualitative data is combined and compared with quantitative data, as in the case of mixed methods research (Patton, 2002).

Quantitative research

The second part of mixed methods research, quantitative design, is used for standardised methods of the data collection where the information is transformed into numbers to enable statistical analysis (Meadows, 2003). There are two main types of quantitative research, the first being experiments with random and non-random designs used to test the impact of a treatment. Secondly, surveys including cross-sectional and longitudinal studies showing trends, attitudes or opinions (Cresswell, 2003).

4.2: Longitudinal methods

Longitudinal methods can be described as the same participants from whom data is collected, over two or more distinct periods. This method is essential for the purpose of measuring social change, as it allows diachronic analysis of that change. It allows the analysis of duration and permits the measurement of differences in a variable from one period to another, and can be used to find the causes of social phenomena, or connection between events that are time-separated (Ruspini, 2000). Longitudinal data are collected in a time sequence that clarifies the magnitude of change, as well as the direction of the change. The study should also continue for a sufficient length of time for the event to have happened, and all the relevant factors to have arisen (*How to review the evidence*, 2000). Serial measurements of a specific variable on the same participant as ageing occurred characterises the longitudinal method (Shock, 1984). This method identified the changes to the older person's living and support needs over the different time periods. The most ideal study of older people would be to provide observations for a continuing time from the age that is considered 'old' (e.g. 65) to death. Since this is impractical, this study has assumed a specific period of a maximum of 18 months for ASPIRE and 13 months for OPERA. The advantages of the longitudinal method are primarily that it allows the observation of a participant over a specified period, so that their specific accommodation and needs changes can be monitored. The study must permit several observations to be made during the timeframe. Due to the observations being over time, events or processes experienced which affect a person's health or functioning in later life can be monitored. Past history of events may be sought at chosen points with the longitudinal approach, thus with repetition or more frequent evaluations the memory error is decreased. Longitudinal observations have the added benefit of being able to identify the effects of physiological events on other variables, which would not otherwise be identified under cross-sectional observations (Shock, 1984).

4.3: Research with older people

There are a growing number of older people who have been traditionally marginalised, but are now becoming involved in research (Mountain, 2003), including expressing their views about the services they receive. There are a number of considerations when working with older people, including the different views, they bring derived from their life experiences. Also, the experience of being involved in research can enhance the older person's feeling of confidence and self worth. There are, however, considerations to be taken into account when involving vulnerable groups such as older people who may have cognitive impairment (Mountain, 2003). Working with older people demands suitably equipped venues, flexible agendas, written information, and in some instances transport (Warren et al., 2003). When dealing with interpreters (people speaking for the older person), care must be taken to make sure the interpreter is ‘in tune’ with the older person and portrays the older person’s view rather than their own. Older people are often considered too frail or too ‘grateful’ to have a major impact on service planning, as demonstrate by the following:

> [older people’s] *expectations are low and they may be too fearful of expressing dissatisfaction to speak out about their experiences of services* (M. Barnes & Bennett, 1998, p. 102)

However, to successfully engage with older people, the project must truly reflect the concerns of older people. All forms of involvement in research require enhanced communication and adequate resourcing in time and finances.

Telephone interviews with older people

Telephone surveys combine the advantages and disadvantages of the self-completion questionnaire and the face-to-face interview. They allow larger numbers of people to be questioned, clarification of questions, and the broadening of explanations. Bias can happen because only those with a telephone are able to answer the questions (Meadows, 2003). Telephone interviews with older people do pose some disadvantages because they rely exclusively on auditory cues, which may be a concern for older people with hearing problems. Telephone interviews have been found to generate the need for more assistance from the interviewer than face-to-face interviews. The response rate for older people can be as low as 50 percent for a cold call (one where there has been no previous introduction or meeting). A follow up survey can have up to a 93 percent response rate when proxies are included (Herzog & Rogers, 1988). There is no conclusive evidence that telephone interviews in relation to health and illness provide lower-quality data (K. Wilson & Roe, 1998; Worth & Tierney, 1993).

4.4: Pilot studies

The importance of pilot studies is to provide researchers with a test of feasibility, and to gain useful knowledge which helps the development of the research. Another advantage is that pilot studies provide a vehicle by which to discover impediments to the forthcoming research (Perry, 2001). The pilot can pre-test the feasibility of a questionnaire or interview schedule, and as such is a crucial element of a good study design. It is planned in anticipation of the main study, and enables advanced warning about where the main research could fail (van Teijlingen & Hundley, 2002). Pilot studies indicate readiness for implementation of the main project, to alert funders. Qualitative work gains knowledge about a little-known phenomenon; however a pilot study may confound this by providing some data which is undoubtedly incomplete (Morse, 1997). The qualitative data collection and analysis of the results in the pilot can be used to assist with the design of the main study, especially if the volunteers recruited are similar for both (Tashakkori & Teddlie, 1998). Since qualitative data is often progressive, researchers can use some or all of their pilot data as part of the main study. Pilot studies with a good design can be most useful for informing the researcher about the process, and at times the likely outcomes (van Teijlingen & Hundley, 2002).

4.5: Chapter summary

This chapter has given a brief overview of the mixed methods design, which is made up of both quantitative and qualitative research, and incorporates longitudinal and pilot studies. Chapter 5 will describe in detail the way these research methods have been used to develop OPERA.

Chapter 5

Methods

Things should be made as simple as possible, but no simpler

Albert Einstein (1879-1955)

This chapter has been divided into parts to enable easier reading: firstly the introduction, next the pilot, then the main study, sample characteristics and lastly validation, reliability, interpretation and ethics. It was necessary for this study to ensure that the inquiry was broad enough in scope to cover the personal comments of the older people, and the people who interacted most closely with them, while also ensuring specific detailed analysis to determine the actual data in the different fields. Mixed methods research was chosen as the primary method to fulfil these needs, because it encompassed rich text qualitative data and the numerical data collected by quantitative design. The study commenced with a qualitatively designed pilot, based upon information from the literature review. After its completion those results were used to form the mixed methods main study. This chapter will describe in detail the process and progress of the qualitative and quantitative analysis which led to the results seen in the following chapters.

The pathway to the decision about where older people lived, commenced with an event such as a sudden worsening of an existing condition, an acute medical problem, or the death of a primary caregiver. This event led to a support needs assessment which established the amount of support the older people required. As noted earlier, support for the sample population was categorised as either high (requiring similar support to rest home care), or very high (requiring similar support to continuing-care hospital level care). The assessed amount of support the older people needed did not necessarily require them to enter residential care, if that support could be provided elsewhere.

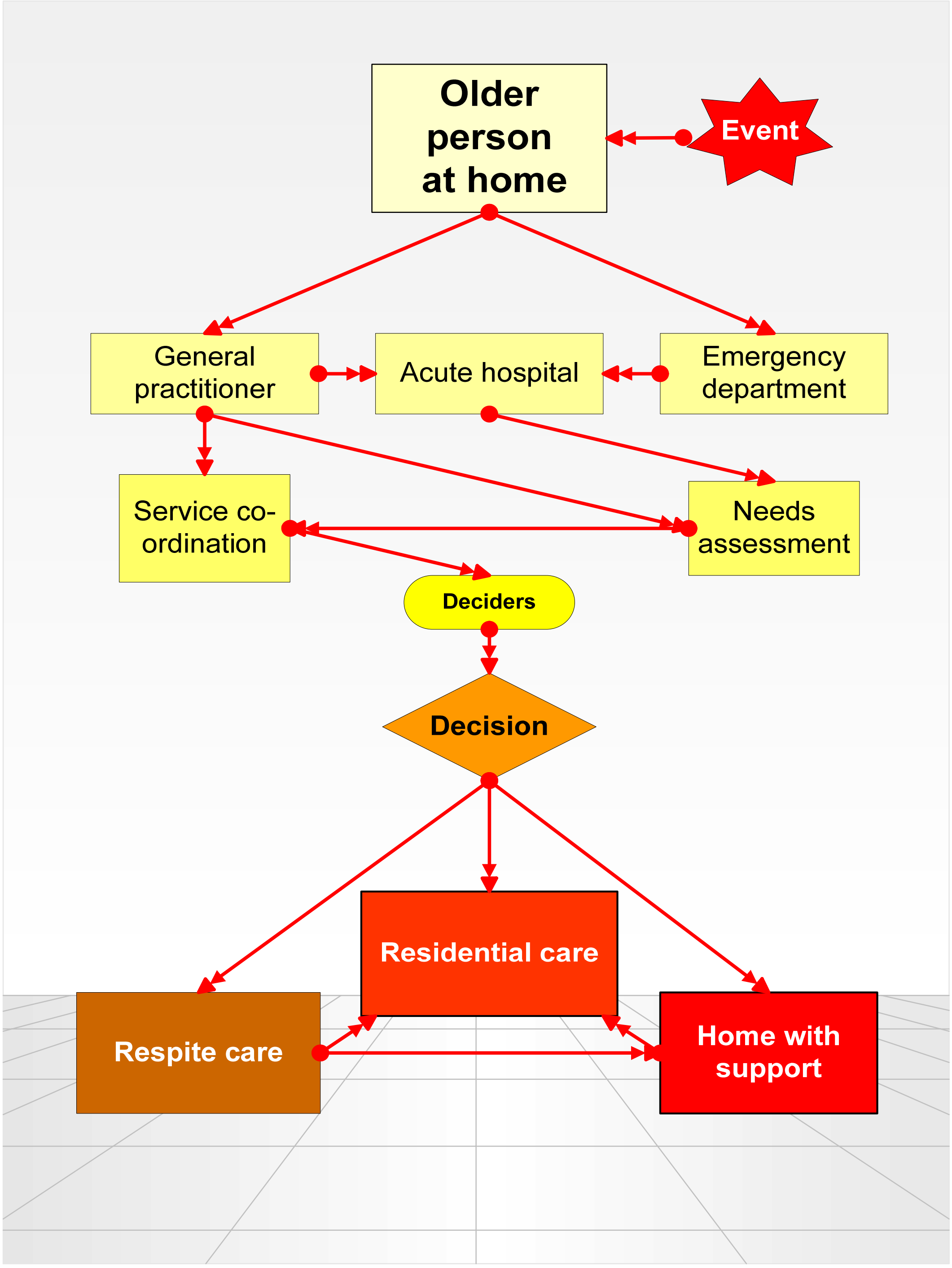

Figure 5.1 Route from an event, to receiving the support needed

The route to the final decision of where the older people should or could live was circuitous, as seen in Figure 5.1. The Pilot study (N=13) was initiated to develop a questionnaire which would help understand the processes and interactions that were happening, and the older person's feelings. This was organised in Lower Hutt, and ranged over a two-month period. The older people in the community were referred by a local researcher from the ASPIRE study, and those in residential care were referred by a retirement village manager. The Main study (N=131), nine months later, was in three cities within New Zealand: Hamilton, Lower Hutt and Christchurch over a 12-month period. Most of the older people (n=94) had a second interview after six months.

5.1: Ethical approval and informed consent

The ethical approval for the pilot study was included in the overall ASPIRE study which was approved on the 4th August 2003, Ethics application number AKX/03/06/177. The ethical approval for the OPERA main study was applied for separately. Ethical approval was granted by the Auckland, Hamilton, Wellington and Christchurch Ethics Committees as an amendment to the ASPIRE trial. The amendment was approved by the lead Ethics Committee, Auckland, on the 14th October 2004 (AKX/03/07/177 PIS/Con V#2, 5/09/03). Clearance and approval for the trial was also gained from the managers of the NASC, MDT, and the residential care facilities.

Informed consent was gained by a signed consent form after the study had been fully explained to the older person. An information sheet was also left with the older person for their reference, which included all the details and contact telephone numbers. Confidentiality and anonymity were maintained at all times by number coding, and all interviews and details were kept in a locked cabinet and on password protected computers.

5.2: Pilot study

Qualitative research methods generally use smaller samples to gather large amounts of detailed information about participants' experiences related to specific events (D. R. Thomas & Hodges, 2004). This method was used with semi-structured face-to-face interviews and gained a broad spectrum of information relevant to the research questions.

Sample

Four groups of people were selected who were located both in their own homes[2], in the community, and residential care[3], as outlined in Table 5.1. The inclusion criteria for the pilot were: any older person living in Lower Hutt who had been assessed as needing high or very high levels of support. The four groups invited to participate were:

(i) Older people (N=13) who were assessed as needing high, or very high levels of support, as determined by the Multi-disciplinary team (MDT), or the Needs Assessment Service Co-ordination team (NASC). High or a very high level of support was consistent with the criteria for residential care entry; however some older people (n=6) were managing at home with substantial assistance.

Table 5.1: Pilot sample groups

N	Groups
13	Older people who lived in residential care, or their own homes
6	Informal primary caregivers (nominated by the older person)
1	Needs Assessment Service Coordination manager
1	Multidisciplinary team member

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[2] Home in this study refers to the home which the older person has lived in within the community, and not part of residential care, although it could refer to a villa or flat within a retirement village.

[3] Residential care is a licensed institution which provides accommodation and services for specific categories of support including rest home, continuing (hospital) and specialist dementia. Residential care is principally a residence for people who are frail because of their age" ("Health and Disability Services (Safety) Act 2001," 2001) .

(ii) The informal primary caregiver (n=6) was nominated by the older person as the person providing advice, help, or other support. The informal primary caregivers (caregivers) were all family members, which included spouses, children, siblings, children-in-law, and a niece. Of those caregivers interviewed, three had relatives in residential care, and three had relatives living at home.

(iii) The managers of the NASC and the MDT were interviewed about the results of the assessment, residence decision-making, and what they thought about the older person's subsequent satisfaction.

Data collection

All groups of people were given an information sheet explaining the study and were encouraged to ask questions about the study at that time. Prior to the study commencing, ethical guidelines were adhered to, ensuring that the older person had: (i) a signed consent form (Appendix, Table A.5.5.); (ii) received verbal and written information about the study; (Appendix, Table A.5.1.) and (iii) had the contact details of the researchers.

All interviews, except for one, were face-to-face (one caregiver was interviewed by telephone). Data gathering was undertaken using a set of open-ended questions, with only pre-arranged prompts being given when necessary, to decrease the likelihood of any potential bias. The questionnaire was checked for validity by two independent researchers, and reviewed prior to use by Professor David Thomas (School of Population Health, Auckland) and Dr Matthew Parsons (Faculty of Medical and Health Sciences, Auckland). The questionnaires were revised in light of their feedback. A questionnaire was then developed for each of the groups of interviewees using both semi-structured and unstructured formats. These were then tested by four older people (selected by an independent researcher) who were willing to assess and give comments, which led to further changes being made.

The interviews with the older people and caregiver lasted approximately 45 minutes, and were related to the older person's residence decision; assessment and family (Appendix, Table A.5.2 and Table A.5.3). The interview questions with the NASC and MDT included general questions about how they made decisions regarding the residence of older people, and there were also specific questions relating to the participants (Appendix, A.5.4).

During the interviews the participants were encouraged to ask questions for clarification. The interviews with the older people, caregivers, NASC and MDT were arranged at a time suitable for them at their usual place of residence, or work. All the interviews were audio-taped, with brief notes also being taken (except for the telephone interview, which was taken in note form, with no audio-taping). The interviews were retained in hard copy, on the computer and on tape. All older people, caregivers, NASC and MDT managers were interviewed once.

Data analysis

Data arising from the audio-recorded interviews were transcribed verbatim into transcripts to ensure accuracy of intent, and to eliminate any potential bias. The data was saved in a Word format on Word for Windows, (Microsoft Corporation, U.S.A., 2003) and later transferred to the software package NVivo 2002, QSR International, Melbourne Australia) (Rich & Patashnick, 2002) where it was analysed. The aim of the analysis was to look for common codes and categories throughout the interview texts which could be grouped to form major themes. The themes acted as a toolkit for the development of a questionnaire for the main study. The themes were developed in 'NVivo' by using a general inductive approach (Patton, 2002; D. R. Thomas, 2006). All the interview texts were read many times to enable categories to be coded throughout. The categories were analysed and grouped into areas of commonality (Cresswell, 2003), which formed the major themes for the pilot, namely: (i) changes, (ii) control, and (iii) placement.

Inter-rater reliability was tested by five transcripts being given to two independent senior researchers to code. The codes were compared and discussed, with similar categories being found throughout. The other transcripts were then re-read to ensure they were in line with those compared. Triangulation occurred by examining the information collected from the caregivers, older people and the referral agencies.

5.3: Main OPERA study

Following the Pilot study, the main OPERA study was designed to explore the decision-making prior to entry into residential care. Also explored were the reasons which enabled people with high support needs to remain living at home or enter residential care. The interviews were conducted in three cities, with an initial interview and another after six months. The main study was planned and implemented using the data from the pilot and the information gained from other similar studies reviewed in the literature. The sequential mixed methods study for data collection was selected for the main study because of the multiple approaches to data collection, analysis and inferences employed in the sequence of events (Tashakkori & Teddlie, 2003). The process is diagrammatically illustrated in Figure 5.2.

All the participants for OPERA were also participants of the ASPIRE trial. Due to the age and frailty of the older people within this group, it was decided the most appropriate method would be face-to-face interviews with all the people in residential care, and also those living at home in the Lower Hutt region. However, due to the distances required to be travelled, telephone interviews were used for people living at home in Christchurch and Hamilton. Telephone interviews were also chosen for some caregivers, for cost reasons. Face-to-face interviews were selected for the NASC. To assist with compliance and time factors, the health professionals' questionnaire was divided into two parts: firstly, generic relating to their general feelings about older people's placement decision: and secondly, specific questions about events leading to the place which was chosen for the older people to live (home or residential care).

Sample groups

The study was based on the older people who, on recruitment into the ASPIRE trial, were living at home in the community. The older people also had a

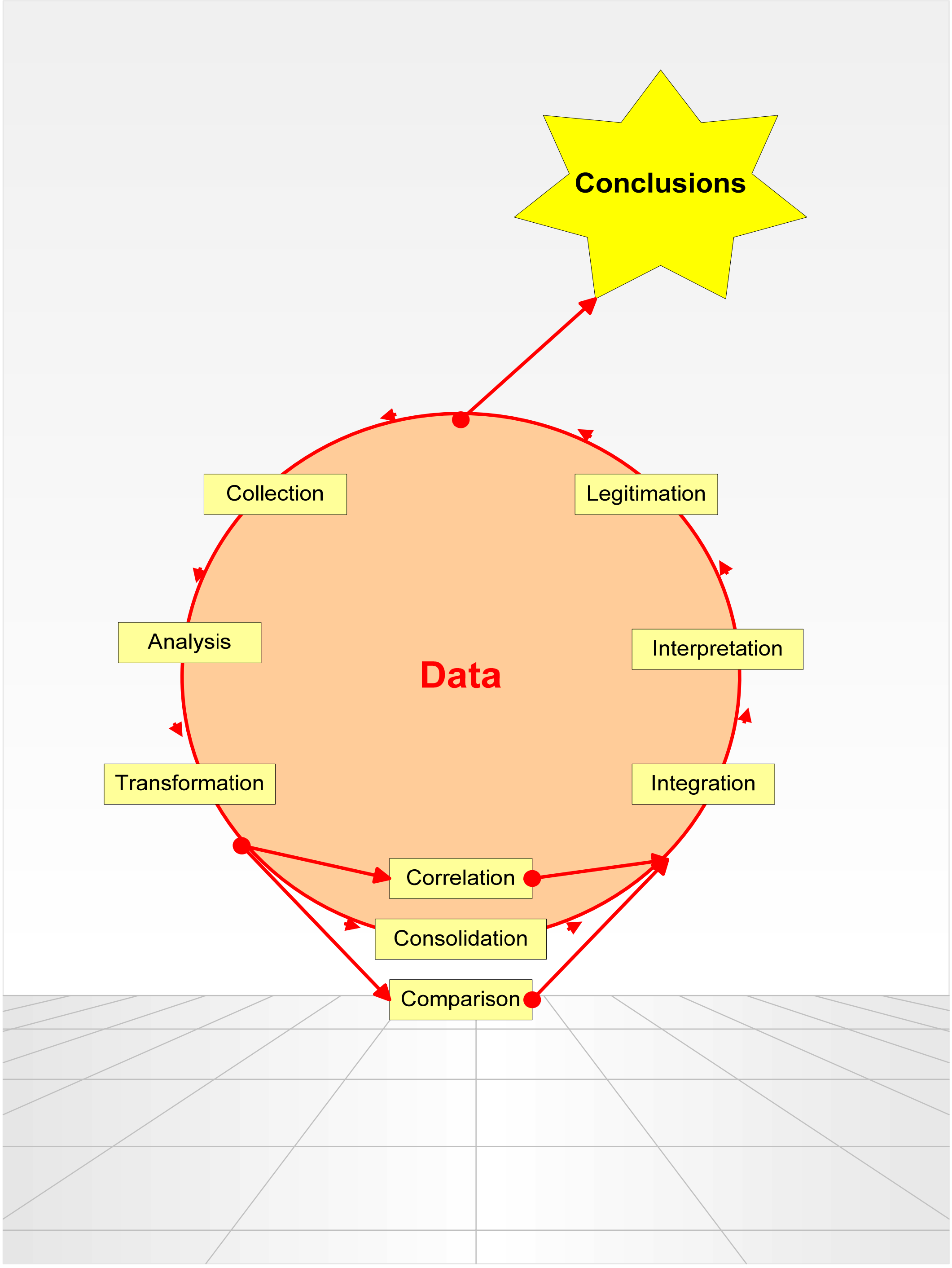


Figure 5.2 Research process using mixed methods

combination of factors which would normally be associated with an increased probability of admission to residential care. Participants from the ASPIRE trial were invited to be included in OPERA in Hamilton, Lower Hutt and Christchurch. The three cities each had a population base in excess of 100,000 and covered both rural and urban areas. Multiple cities were used to obtain a larger number of older people than one city was able to produce, within the recruitment time. Due to interviews being conducted by telephone in Hamilton and Christchurch, the older people living at home without a telephone in these cities were excluded. Three groups of people were involved, as shown in Table 5.2.

Table 5.2: Main OPERA sample groups

N	Sample groups
131	Older people with high support needs
24	Caregiver (as nominated by the older people)
1	NASC group

(i) The older peoples' recruitment was for approximately one year, from November 2003 to December 2004. Older people in the ASPIRE trial were asked if they wished to participate by a researcher in each of the three cities, and were advised they could withdraw at any time. At times the researcher did not invite older people to participate due to a number of undefined reasons. As this pre-selection occurred prior to entry into the study, it was beyond the control of OPERA.

(ii) The caregivers were nominated by the older person as the people who gave them support. Not all older people had caregivers, or wished to identify people as such. Twenty-four caregivers were interviewed.

(iii) The NASC functioned as a placement and support co-ordination broker for people assessed with high or very high level of support needs. The NASC received the referral from the MDT stating the level of support needed for the older people, and then home support or residential care was organised.

(iv) Power analysis was necessary to be certain that the sample size for the study was sufficiently large to ensure the test conclusions were statistically valid to the 95th percentile (Siegel & Morgan, 1996). Elizabeth Robinson, statistician at Auckland University, was consulted to ensure the study sample size was sufficiently large. It was agreed that a sample size of 100 people, of whom one-third may move into residential care during the study, would have 90 percent power at the 0.05 level of significance to show a difference of 25 percent between the two groups. The sample size of 100 was increased to 131 to ensure a reasonable number of people eventually going into residential care. Of the 131 participants selected, 28 were subsequently admitted to residential care.

Data gathering methods

Face-to-face and telephone structured interviews with both open and closed questions were used. In order to evaluate the clarity and language of the main study questionnaire, a draft was tested prior to commencement of the interviews, by having a random small sample of the older people complete the interview. Critical review of the questionnaires was carried out by two senior researchers as described in the Pilot. A final review was undertaken with a group of four older people, to test the questionnaire. Structured face-to-face or telephone interviews were given to the older people, their caregivers and the NASC. Telephone interviews could have been more difficult for those older people with hearing difficulties, but were more convenient for those not wanting visitors at home. This method also resulted in a significant time saving for the researcher (Herzog & Rogers, 1988). All questionnaires were a mixture of both qualitative and quantitative designs to allow for maximum data collection.

Data collection procedures

The collection procedures were the same as described within the Pilot study. The information sheet for the Main study which was given to the participants is in Appendix A.5.6

Telephone interviews with the older people and the caregivers were arranged at a suitable time. All telephone interviews were carried out by the same researcher and lasted approximately 20 to 30 minutes. The data were entered into a computer via a pre-prepared document while the interview was progressing. The older people who were living in residential care or were living in the Lower Hutt region were interviewed face-to-face and the interview tape-recorded. A time for the interview was arranged with the facility and the older person, after prior consent had been given. The interviews took place in the older person’s room and lasted approximately 30 minutes. Prior to the face-to-face interview occurring with the NASC, a letter and information sheet was sent to explain the study and to request a meeting time. In order to gain an understanding of the NASC's perspectives, the NASC questionnaire had general questions regarding how they responded to referrals and specific questions regarding the older people participating. Data saturation was reached after 12 older people had been discussed with the NASC. A second interview was arranged at six months with the older people, caregivers, and the NASC.

Quantitative information was downloaded from the ASPIRE trial to add to the quantitative and qualitative data collected from the 131 OPERA interviews. The information received from the ASPIRE trial was: personal data, health status, social networks, dependence, cognitive functioning, prior admission to hospital, and caregiver stress.

Data analyses

The data were analysed in two parts: the qualitative theme building and the quantitative data analysis from OPERA and ASPIRE. The qualitative data which included the data from the older people, caregivers and NASC were entered verbatim into 'NVivo' in order to build categories and develop themes. The qualitative data analysis has been more fully covered within the pilot study section.

The quantitative data from OPERA and ASPIRE were loaded into the statistical programme SPSS for Windows 12.1 (1999) (Green & Salkind, 2004; Puri, 2002). The data were divided and labelled into specific variables, which linked to the research questions and overall objectives. The data were first grouped (reversed where necessary), scales formed, and variables selected for testing. A Kendall's tau-b non-parametric correlation with 'home or residential care' as the dependent variable was performed, using all the nominated variables to test for significant correlations. Next, chi-square was performed to test for goodness of fit of the dependent variable (home or residential care) on the independent variables. Pearson's r parametric correlations were performed using 'the percentage of time from study entry to residential care entry' as the dependent variable, to test for the correlation with the other variables. The results of the Pearson's r were compared with the results of the Kendall's tau-b correlation to check for consistency.

Binary logistics regression using the dichotomous dependent variable 'residential care or home' was further used with the independent variables to see the effects of each independent variable when controlling for other variables (in contrast to the correlations which only looked at one variable at a time) (Altman, 1996). Prior to the regression tests, variables potentially measuring the same dimension were examined to check for significant relationships (at greater than $p = 0.3$) and which could cause confounding effects by duplication of the same variables. Instrumental Activities of Daily Living (IADL) and Activities of Daily Living (ADL) were found to have a significant relationship, so ADL which had a lower relationship to the dependent variable was not used.

The quantitative questions from the OPERA questionnaires (Appendix, A.5.7-10) were scored either on the Likert scale (Maurer & Pierce, 1998; D. R. Thomas, 2004), where the answer was rated from strongly agree (5) to strongly disagree

(1), or a similar (4 to 1) scale. Question three on the older people's questionnaire, regarding the older people's efficacy, was the combined score of five questions adapted from the Pearlin and Schooler's (1978) original Mastery scale (D. R. Thomas, 2004). Efficacy was chosen as a way of judging the older persons self esteem and their sense of value or worth (MacArthur & MacArthur, 2004)

The ASPIRE data was downloaded in Excel spreadsheets from the Clinical Trials Research Unit at Auckland University, where the ASPIRE trial was being managed. The data files downloaded were from forms: (i) 'B1 long', which included the initial, first (3rd month), third (12th month) and fourth (18th month) interviews, (ii) 'B1 short' which included the shorter second interview (6-month), (iii) 'B2' caregivers 'long' and (iv) 'short', (v) 'X' adverse events (vi) 'Form A' giving gender, ethnicity and other relevant details. All these data were checked for duplication, cleaned and corrected. The forms were then checked to make sure all data names were identical. The data was then transferred to SPSS and forms 'B1 long' and 'short' were merged so the data would be contained on one spreadsheet, and similarly the 'B2 long' and 'short' data forms were combined. A frequency check of all variables ensured that the data were correct. Figure 5.3 shows the progression of the analysis.

ASPIRE used a comprehensive geriatric assessment tool called the Minimum Data Set – Home Care (MDS–HC) as part of its questionnaire (Appendix A.5.25). The MDS-HC allowed the assessment of multiple key domains such as: function, health and support. Summary scales were developed from the MDS-HC by the Outcome measurement and resource utilisation groups, for the InterRAI organisation (*Outcome measurement and resource utilization groups*, 2003) and validated (Hawes et al., 1995; Mor et al., 1997; J. Morris et al., 1994). Some examples of journal articles referring to the validity and reliability of the scales used in this study are: (i) Activities of daily living self-performance hierarchy scale (ADL) (J. Morris, Fries, & Morris, 1999); (ii) Cognitive performance scale (J. Morris et al., 1999); (iii) MDS depression rating scale (Burrows, Morris, Simon, Hirdes, & Phillips, 2000); (iv) Changes in health, end-stage disease and signs and symptoms (Hirdes, Frijters, & Teare, 2003); (v) Pain scale (B. E. Fries, Simon, Morris, Flodstrom, & Bookstein, 2001). The following is a comment from one of the reviews:

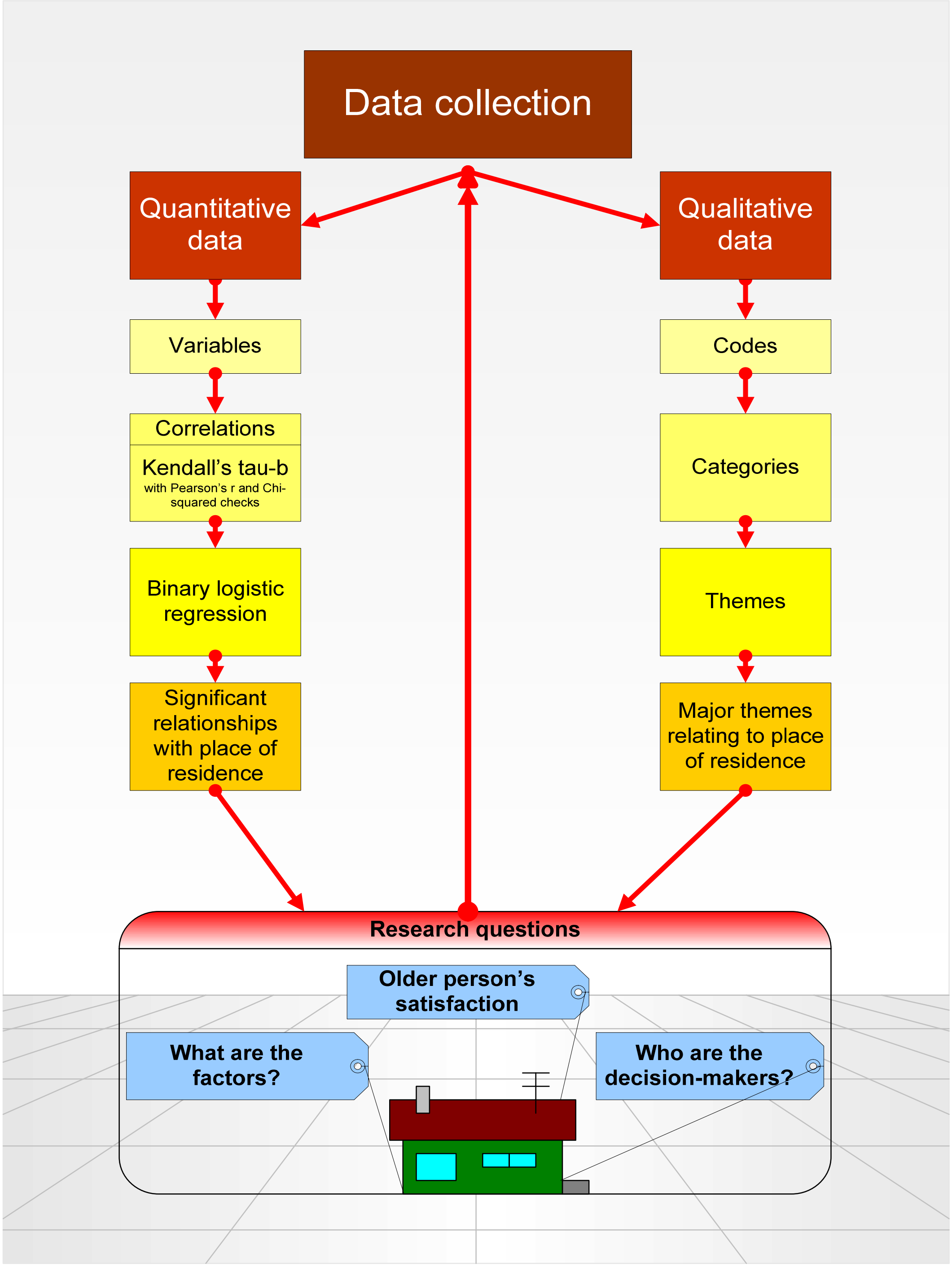


Figure 5.3: Progression of analysis

> *Results demonstrate that MDS data gathered in a research effort attain reliabilities that make such data useful. MDS items met a standard for excellent reliability in key areas of functional status, such as: cognition, ADLs, continence, and diagnoses.* (Hawes et al., 1995, p 172)

Both scales and individual questions were selected out of the ASPIRE questionnaire, which were thought appropriate for OPERA. The scales were:

(i) Cognitive performance scale (CPS).

This hierarchical scale used to rate the cognitive status of the older people was based on: short-term memory, cognitive skills for daily decision making, expressive communication, and eating. The scores were derived from these four items based on the individual's impairment level, to give an overall CPS score ranging from '0' no impairment to '6' maximum impairment. This score is equivalent to the Mini Mental State Examination (MMSE) scores (Table 5.3) which is the test for severe cognitive impairment (J. Morris et al., 1994). Figure 5.4 highlights the process in detail. Specific details and the calculations which were performed to construct the derived variables, using 'if' statement in SPSS are in Appendix Tables A.5.11–13.

Table 5.3: Cognitive performance rating scale with equivalent MMSE

CPS score	Description	Equivalent Average MMSE
0	Intact	25
1	Borderline intact	22
2	Mild impairment	19
3	Moderate impairment	15
4	Moderate/severe impairment	7
5	Severe impairment	5
6	Very severe impairment	1

MMSE = Mini Mental State Examination

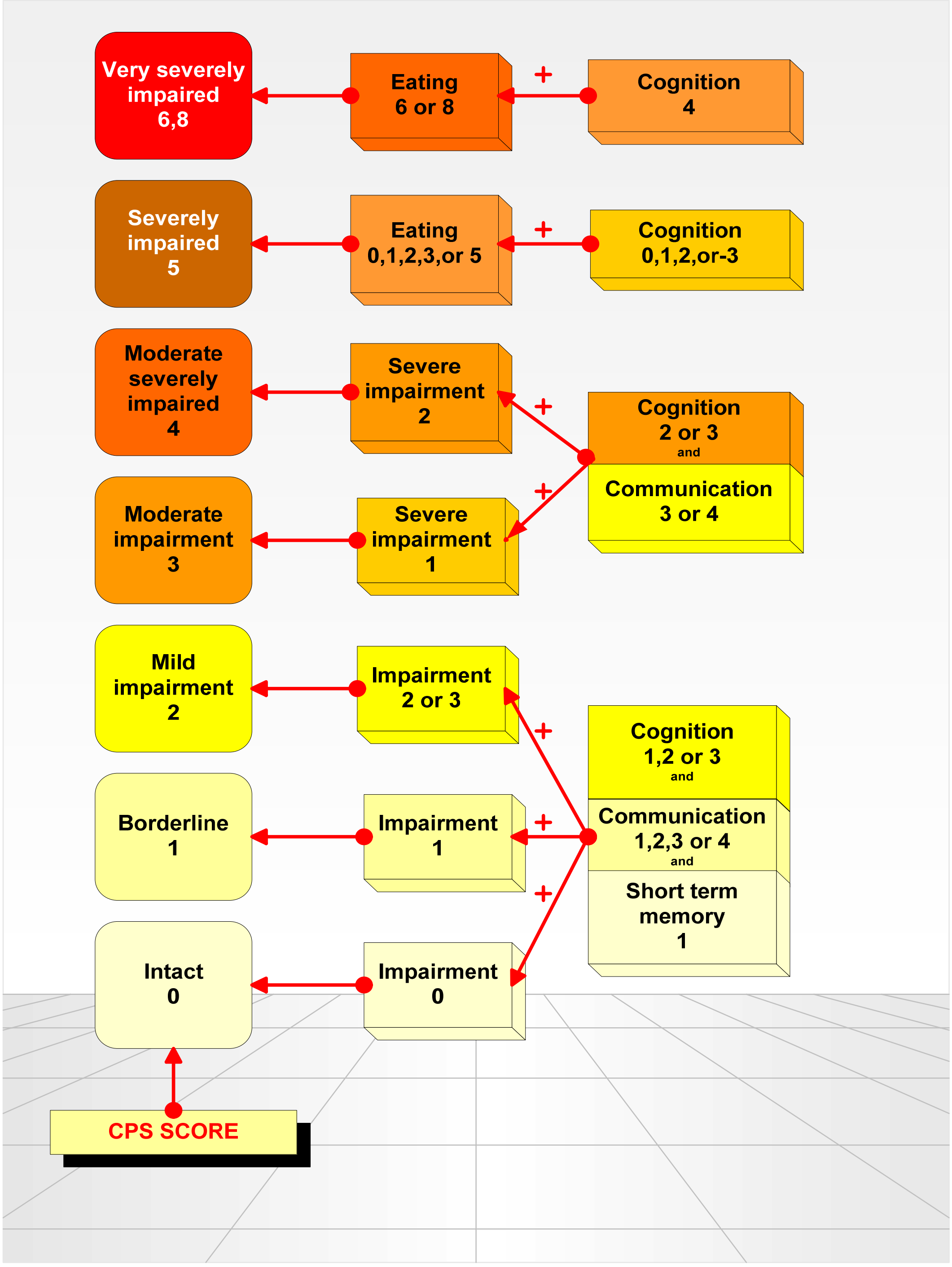


Figure 5.4: Cognitive performance scale scoring

(ii) Depression rating scale.

This scale based on the seven items in Table 5.4 was used to indicate depression amongst the older people. Each of the seven items is coded (on a scale of 0 to 2) according to symptom frequency, resulting in a possible depression rating score of ‘0’ no depression, to ‘14’ severe depression.

Table 5.4: Depression rating scale

Score	**Indicators of depression**
0, 1 or 2	Negative statements
0, 1 or 2	Persistent anger
0, 1 or 2	Expressions of unrealistic fears
0, 1 or 2	Repetitive health complaints
0, 1 or 2	Repetitive anxious complaints
0, 1 or 2	Sad, pained, worried facial expression
0, 1 or 2	Tearfulness

0 = Indicator not exhibited within the last 30 days, 1= Indicator exhibited up to five days a week, 2= Indicator exhibited almost daily

A score of equal to, or greater than three was considered as either minor or major depression, and worthy of further evaluation. This scale has been validated against the Hamilton Depression Rating Scale, the Cornell Scale for Depression and psychiatric diagnosis. However, the validations could have limitations due to the study having relatively small numbers (N=82) and also being within only two facilities (Burrows et al., 2000; *Outcome measurement and resource utilization groups*, 2003).

(iii) Instrumental activities of daily living summary (IADL) scale.

The suite of IADL questions consisted of three scales: (i) ‘difficulty’ which measured the older person’s difficulty with ordinary housework, meal preparation, and using the telephone; (ii) ‘involvement’ was based on the level of participation the older person had with the three items in the difficulty scale; and (iii) ‘summary’ was based on the three items, housework, meal preparation and use of the telephone and four others; managing finances, managing medications, shopping and transportation (Table 5.5). Due to similar items being used in the three scales and the confounding effect this may have had on the statistics, only the summary scale was used. The IADL summary scale was based on the seven self-performance items mentioned above, with each item scoring from 0 to 3 according to the level of ability. The individual items were totalled to give a score ranging from 0 no problems to 21 total dependence. The higher the score, the more dependent on others the older person was in performing the activities.

In order to examine the differences between people with high and low IADL scores, and also to compare the two groups of people with other variables, it was necessary to determine a suitable cut-off point between high and low IADL scores. No such point was found within the literature for the IADL scale. The scree method (Lance, Butts, & Michels, 2006) of determining a cut off point was used. The decision of which point to choose for cut-off aimed merely at encompassing what is called ‘non-trivial’ common variance (Cattell, 1966). The scree method determined where the area of trivial and non-trivial data was to be found. The scree plot showed an elbow at level 10 (out of the 0- 21 range) as the cut-off point on the IADL frequency data (Appendix Figure, A.5.1).

Table 5.5: Instrumental activities of daily living

Score	Indicators of difficulty and involvement with instrumental activities of daily living
0 to 3	Meal preparation
0 to 3	Housework
0 to 3	Managing finances
0 to 3	Managing medications
0 to 3	Using the telephone
0 to 3	Shopping
0 to 3	Transportation

0 = Independent, 1 = Required some help, 2 = Required full help, 3 = Activity performed by others

(iv) Activities of daily living self-performance hierarchy scale (ADL).

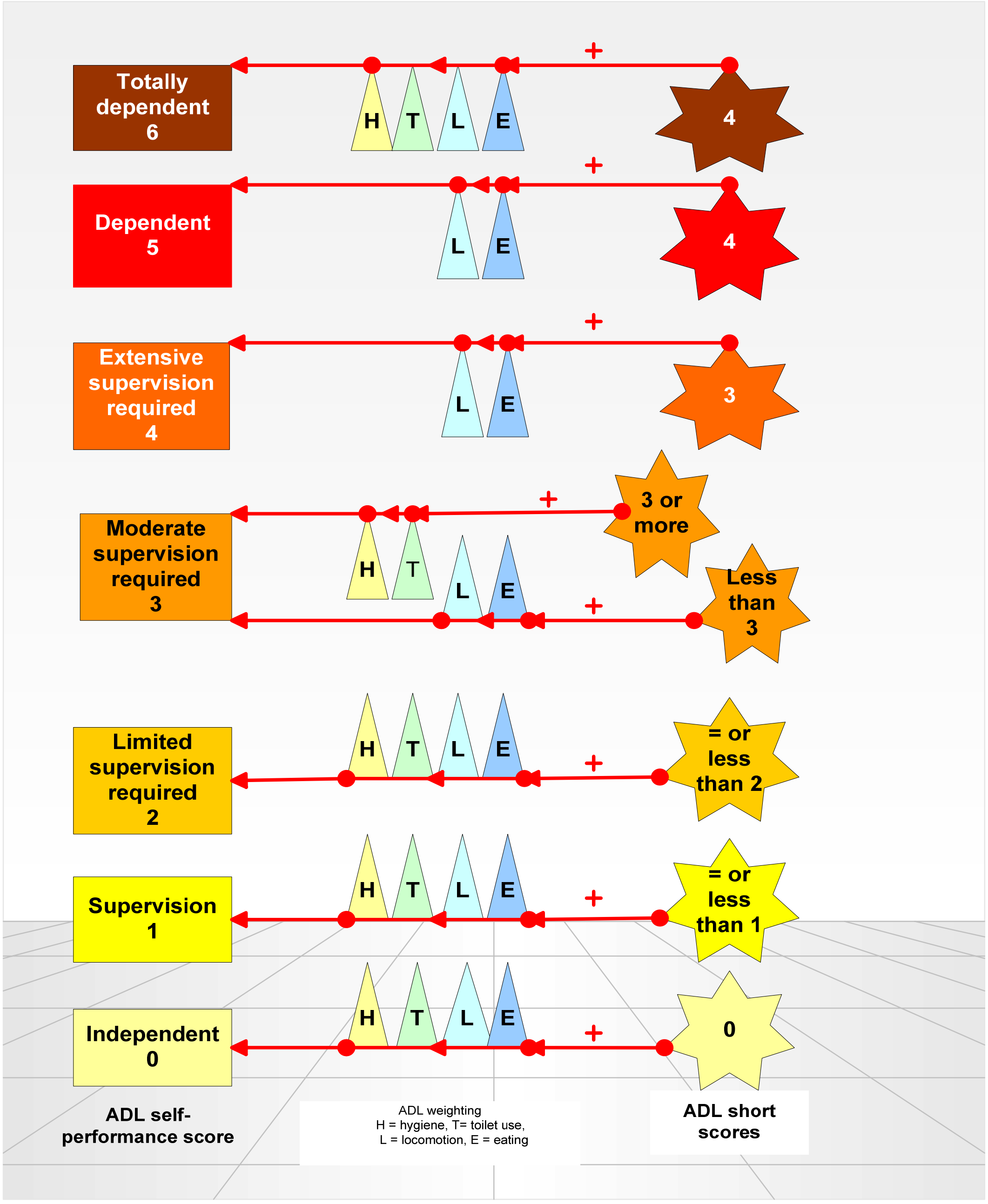
Here also is a suite of three scales within the ADL group; the ‘short’ and ‘long’ ADL scales, and the ‘self-performance hierarchy’ scale. Only one of these scales could be used due to the confounding effect of having similar items tested. The items in these three scales were similar, but the self-performance hierarchy scale was chosen for use within OPERA due to its ability to measure the disablement process, rather than just the reduction in function. It looked at the items, personal hygiene (lost early in the deterioration process), toilet use and locomotion (middle losses), and eating (late loss). The self-performance hierarchy scale ranked the lower scores for early loss of ADL function (hygiene) less than those functions lost at a later stage, such as eating. The individual scores from the base ADL ranged from 0 to 4, but the ADL self-performance hierarchy scale transforms the base ADL to a 7 point hierarchical scale (Table 5.6). The calculation in SPSS is shown in Appendix Table A.5.14.

Table 5.6: ADL Self-performance hierarchical scale

Score	Classification description	Use of four ADL items
0	Independent	All four score 0
1	Supervision required	All four score 1 or less, and at least one scores 1
2	Limited impairment	All four score 2 or less and at least one scores 2
3	Moderate assistance required	Eating and locomotion both score less than 3 and personal hygiene and toilet use both score 3 or greater
4	Extensive assistance required	Eating or locomotion score 3
5	Dependent	Eating or locomotion score 4
6	Total dependence	All four score 4

Note: The calculations did not allow for toilet or hygiene if they were individually scored 3 or 4 (with no other significant scoring for that person). Where toilet or hygiene alone was scored as 3 or 4 this was calculated as a 2 on the self-performance hierarchy scale. ADL = Activities of daily living.

The rather convoluted development of the ADL self-performance hierarchy scale is illustrated in Figure 5.5.



ADL= Activities of daily living

Figure 5.5 Development of the ADL self-performance hierarchy scale

(v) Changes in health, end-stage disease and signs and symptoms (CHESS).

The CHESS scale was developed to detect frailty and instability in health. Firstly, a base scale was created by counting across the six health symptoms shown in Table 5.7. The scoring for the base CHESS is shown in Table 5.8. Secondly, the base score was weighted by adding three categories measuring personal decline (Table 5.9). Each of the three categories of decline was calculated as 1, and added to the base score to result in a six-point scale, with scores ranging between 0 (no instability) to 5 (maximum instability) shown in Appendix Table A.5.15. It has been shown in the long-term care population that a clear difference existed between all six levels of the CHESS scores (Hirdes et al., 2003).

Table 5.7: CHESS base health symptoms

Assessment item
Vomiting
Dehydration
Leaving food uneaten
Weight loss
Shortness of breath
Oedema

Table 5.8: Scoring for the CHESS base symptoms

Score	Description of classification
0	No base symptoms
1	At least one of the base symptom present
2	Two or more base symptoms present

Table 5.9: CHESS base score variables

Score	Variables used for the final calculation
1	Decline in cognition
1	Decline in ADL functions
1	Decline in overall health

(vi) Pain scale for the minimum data set.

Pain frequency and intensity are calculated together to form a four-point scale (0 no pain to 3 maximum pain) (Figure 5.6). Within the residential care population the pain scale has been shown to be highly predictive of the amount of pain suffered by the older people (J. Fries, 2003; *Outcome measurement and resource utilization groups*, 2003). The formulae used for the Pain scale calculation in SPSS are shown in Appendix Table A.5.16.

(vii) Caregiver reaction assessment

This scale for caregiver stress was not part of the MDS-HC group. The caregiver reaction assessment (CRA) instrument was chosen due to its ability to both discover changes over time and differences within different circumstances (Given et al., 1992). It was also chosen because it did not only look for the negative aspects of caregiving, thus giving a much rounder assessment of the real feelings of the caregiver. The data from the ASPIRE caregiver questionnaires were downloaded, checked and merged within SPSS (similar to the older people's data). The CRA was a multidimensional assessment which was developed to test the reactions of family members when caring for older people who had severe chronic disabilities. Specific aspects of the caregiving situation were assessed, including both negative and positive dimensions of caregiving reactions. The CRA had 24 items, and factor analysis provided five subscales: schedule: esteem: family support: health: and finance. These were all rated for relevance. Respondents answered on a five-point Likert scale. These questions form one scale with a range from 0 no stress to 120 maximum stress. Appendix Table A.5.17 illustrates the questions asked within each section of the scale (Given et al., 1992). The coding scheme ranged from 1 strongly disagree to 5 strongly agree. The final score signifies the level of stress the caregiver was experiencing. The stress levels of caregivers at: (i) all interviews, all caregivers, (ii) with the older person in residential care, and (iii) with the older person at home, are shown by way of the means tables in Appendix Table A.5.19. Appendix Table A.5.18 shows the SPSS calculations used for the CRA.

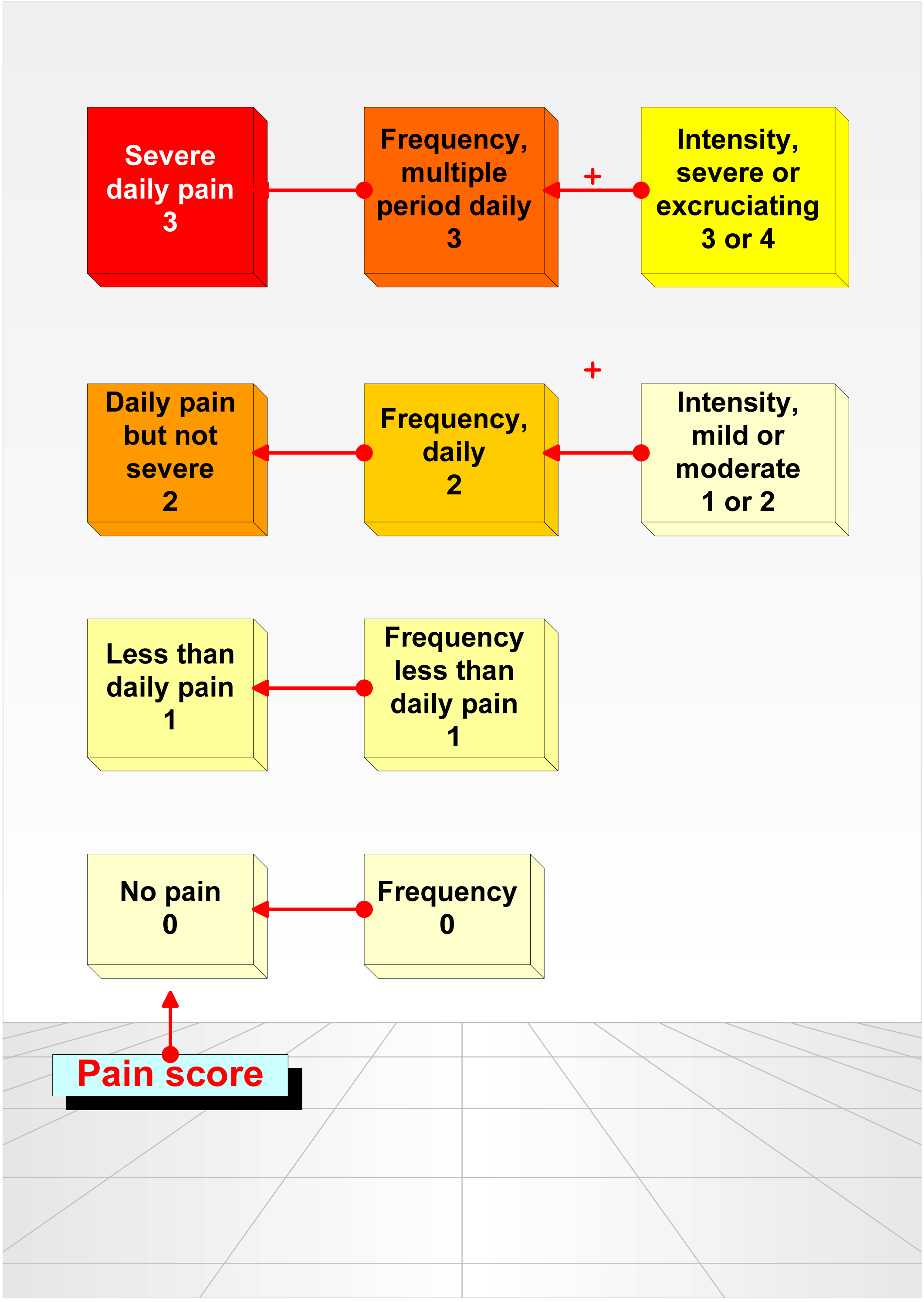


Figure 5.6: Pain scale

The individual questions selected out of the ASPIRE questionnaire were those relating to questions about support, and contact with family and friends. For these questions the questionnaire was rated as ‘a’ to ‘f’, but has since been numerically scored by ASPIRE as 0-5. This scoring has been slightly changed to reflect the direction of the scale, ranging from close contact to no contact. Where ASPIRE had rated ‘no relatives, siblings, neighbours, children or friends’ as 0 this has been changed to 6 (Appendix A.5.20). The other individual questions from the ASPIRE questionnaire were related to the older person’s loneliness or being home alone.

5.4: Sample characteristics

This section will outline the characteristics of the study population at the onset and also at the individual interviews. The three populations discussed are the Pilot (N=13), OPERA (N=131), and ASPIRE (N=569). At the commencement of the studies most of the older people were living at home and recently had some event or worsening of their condition (7 from the Pilot and 9 from OPERA were living in residential care at study commencement). This event led to the older person’s assessment of their support needs, to ensure they were receiving adequate support to maintain a safe lifestyle.

The majority of the older people within the three studies were classified as needing high levels of support, female, and of New Zealand European descent, as seen in Table 5.10. Overall the percentages were similar across OPERA and ASPIRE for the existing conditions, except that a much higher percentage of OPERA participants had strokes, and more people with dementia were in ASPIRE. There was a greater percentage of older people with caregivers in ASPIRE and the Pilot than in OPERA. Figure 5.7 illustrates the ages of the older people and emphasises that the majority were over 80 years.

Table 5.10: Older people's demographics

Older people	**Pilot**		**OPERA**		**ASPIRE**	
Age	N = 13	%	N =131	%	N = 569	%
65-69	1	8	6	5	29	5
70-74	3	23	16	12	70	12
75-79	3	23	30	23	116	20
80-84	4	31	27	21	138	24
85+	2	15	52	40	213	37
missing	0	0	0	0	3	1
Mean	78		82		82	
Standard deviation	7		7		7	
Median	78		83		82	
Residing at study commencement						
Residential care	7	54	9	7	0	0
Home	6	46	122	93	569	100
Female	9	69	86	66	368	65
Ethnicity						
New Zealand European	11	85	118	90	495	87
New Zealand Maori	2	15	4	3	10	2
Pacific Islander	0	0	1	1	3	1
Other	0	0	8	6	61	11
Support needs						
High	9	69	114	87	469	82
Very high	4	31	17	13	100	18
Health and disability						
Dementia	3	23	12	9	99	17
Fractures	1	8	48	37	191	34
Angina	1	8	52	40	218	38
Strokes	5	38	89	68	199	35
Older people with caregivers	6	46	24	18	284	50

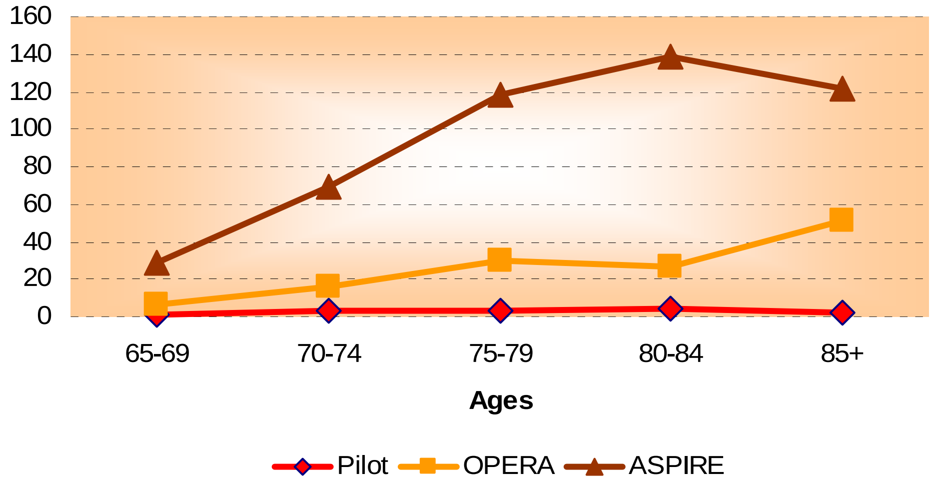


Figure 5.7: Number of people in the age groups

The pilot

The assessment initiating events varied with most people having a medical event which required them to be admitted to an acute hospital. Only the people with worsening dementia (2), and those assisted by someone who was not coping, were not admitted to an acute hospital. However, approximately half the people (n=5) who were referred to an acute hospital were admitted to residential care on discharge. Overall seven people from the pilot were admitted to residential care, while six stayed in their own home.

OPERA

OPERA recruitment was similar in Lower Hutt and Christchurch, n=53, n=69 respectively, but much lower from Hamilton at n=9. Within OPERA, 28 people (21.37%) were admitted to residential care by the end of the study, and 11 people (8.39%) died. There were 94 people who had a second interview six months after the initial interview, and the Needs Assessment Service Co-ordination team comprehensively discussed 12 of the older people.

ASPIRE

There were up to five ASPIRE interviews, which were held at the following times: on admission to the study (immediately after the older person's support needs assessment), and at intervals of three months, six months, 12 months, and 18 months. The numbers of older people participating decreased with every interview, however the drop in numbers being most marked for the 18-month interview. At commencement the participant numbers were 569, but by the three-month interview there was an 11 percent participant drop, continued by decreases of 17 percent, 32 percent and 71 percent at subsequent interviews. (People who entered residential care continued participating in the interviews.) The reason for the decrease in numbers was due in part to deaths and withdrawals, but also to some people having commenced the study later, and therefore not able to reach the 18-month interview prior to the study closure.

OPERA and ASPIRE

A set of tables was developed which used the mean, median and standard deviation scores to describe what the older person's condition was at each of the interviews, in residential care and at home. The tables show the scales and other variables which were considered as possible indicators for residential care entry. The scales and questions pertain to the older person and caregiver. The data in Table 5.11 were self-reported at the initial assessment, and compares the level of the older person's disability between the two studies. In most cases the level of disability and caregiver stress was slightly higher in the ASPIRE group. This was possibly due to the selection of participants for OPERA by the researchers. Those participants who were very cognitively impaired, or otherwise severely disabled, may not have been selected, although these were not criteria for exclusion.

Table 5.11: Baseline older people demographics - scale measurements

	ASPIRE total	**OPERA**	**ASPIRE minus OPERA**
Cognitive performance scale (range 0-6)			
Number	566	131	435
Mean	1.35	1.02	1.45
Standard deviation	1.21	0.84	1.29
Median	1.00	1.00	1.00
Depression rating scale (range 0-14)			
Number	566	131	435
Mean	3.09	2.74	3.19
Standard deviation	0.71	2.20	2.84
Median	2.00	2.00	3.00
Instrumental activities of daily living (range 0-21)			
Number	566	131	435
Mean	10.24	8.36	10.8
Standard deviation	5.80	4.88	5.94
Median	10.00	8.00	11.00
Activities of daily living (range 0-6)			
Number	566	131	435
Mean	0.46	0.54	0.53
Standard deviation	1.12	0.80	1.19
Median	0.00	0.00	0.00
Changes in health end-sage disease, signs, symptoms (range 0-5)			
Number	566	131	435
Mean	2.43	2.48	2.41
Standard deviation	1.14	1.03	1.17
Median	2.00	3.00	2.00
Caregiver reaction scale (range 0-120)			
Number	273	47	226
Mean	74.59	73.32	74.85
Standard deviation	9.07	8.53	9.17
Median	75.00	73.00	75.00

Note: Those participants who were in OPERA were not counted in the ASPIRE numbers

Sample at each interview

To gain an idea of the concerns of OPERA as a whole, and also those people within residential care and living at home, the mean scores were compared, as seen in Appendix Table A.5.21. The comparison was made with the mean scores from a scale of 1 (great concern) to 4 (no concern) in all the variables except for variable 'the family doing too much', which was on a scale of 1 to 5. Within the total group section it was identified that as the time progressed to the second interview the older people were getting more worried about the family doing too much and were much lonelier. Conversely at the six-month interview they were a little happier with the community support they were receiving than at the initial interview. With the people living at home at the second interview, they felt they were not coping so well and were definitely lonelier. The people in residential care also stated they were lonelier at the six-month interview.

The ASPIRE group was examined for health status also by using the mean scores. The group scores were divided into three sections the total group (Appendix Table A.5 22), the older people living at home within ASPIRE (Appendix A.5.23), and the older people living in residential care (Appendix A.5.24). The scores are divided by interviews, with the six-month interview being omitted for some of the scales due to the shorter questionnaire at this interview. The scales used for ASPIRE were of varying lengths but the higher the number the greater the disability. The mean scores for the total group varied little between the five interviews except for depression, which decreased and was least at the 18-month interview. This was true for both those people living at home and also within residential care. One interesting comparison between people living in residential care and at home was that the mean dependence level for Instrumental activities of daily living (IADL) scale was much higher for people within residential care, whereas at home the older people's mean dependence with IADL appeared to improve over the 18 months. This was also true for the Activities of daily living scale.

5.5: Validity and reliability

> *Rigor necessitates that researchers attempt to be fully accountable for the data collection, analysis and interpretive methodologies*
> ((Tashakkori & Teddlie, 2003, p. 354)

Validity asks the question: 'Did the research measure what it was supposed to measure?' Reliability is the degree of consistency of the measure (Becker, 2000). Validity and reliability in mixed methods research is made up of several parts: credibility; trustworthiness; dependability; conformability; and transferability. In quantitative research this is tested by internal and external validity. The qualitative research validity is tested by the following five different measures: descriptive; interpretive; theoretical; evaluative; and generalisability (Tashakkori & Teddlie, 2003).

To ensure that data arising from OPERA were reliable and valid, several methods were employed, including triangulation between the qualitative and quantitative data. Triangulation was described by the pioneering methodologist Donald T. Campbell as saying: "*that every method has its limitations, and multiple methods are usually needed"* (Patton, 2002, p. 247). Four different triangulation types were used to strengthen this study:

(i) data triangulation, or data from a variety of different people who interacted and talked about the older people;

(ii) investigator triangulation, where several different researchers were used, such as the ASPIRE researchers in the three centres;

(iii) theory triangulation, where the data was looked at from multiple perspectives within ASPIRE and OPERA; and

(iv) methodological triangulation, where both qualitative and quantitative methods were used to study the questions.

5.6: Interpretation of statistics

Inferences could be made about the larger New Zealand population of older people in general from this study, with a certainty that the sample mean was within 95 percent of the general older people population mean. The generalisation of the findings rather than the information gained about the individual person was where the usefulness of the research lay. Studies are relevant to predict what might happen with future populations, not to a particular person (Altman & Bland, 1998). However, these are only estimates of the values which apply to the whole population (Bland & Altman, 1986). In published papers there are many significance tests, which if the researcher goes on long enough one in 20 will prove significant by chance alone (Bland & Altman, 1995). Areas for review and research in this study were identified at the onset, and were derived from the literature review and pilot study.

5.7: Chapter summary

The methods for the pilot study allowed for full analysis of the qualitative data produced from the semi-structured interviews, while the main study was more structured and used a mixed methods approach, to allow the quantitative and qualitative data to be fully analysed and recorded. A rigorous ethical procedure ensured the highest standards of ethics were maintained at all times. The different groups of interviewees allowed for an overall view of the decisions, factors and the older people's satisfaction with that decision. The qualitative themes were found using NVivo and numerous readings and re-readings. The quantitative data, using SPSS, went through consolidation, correlation and regression to ensure accurate findings. The assessment tools for the scales were explained in full, similarly the validity and ethical procedures.

Chapter 6

Findings

What you can do or think you can, begin it boldness has genius, power and magic in it. Johann Wolfgang von Goethe (1749-1832)

The purpose of scientific research is to communicate with others, by the publication of results (Lima, 1998). For ease of reading and clarity, the study findings have been divided into two parts: Part 1 which develops the model and the findings from the qualitative data: Part 2 presents the quantitative data findings. Broadly, the results are presented according to the research questions: (i) the risk factors for the older person in relation to residential care entry in New Zealand, (ii) the decision-makers for where the older person would live (home or residential care), and (iii) the older person's satisfaction with the residence decision.

Part 1: Older people; coping, decision-makers and satisfaction

In order to have a model which answered the research questions, the findings reported in Part 1 have been sequentially structured through three Models. The model development illustrated in Figure 6.1 is:

(i) Model 1. Data from the literature review formed the basis for the model.

(ii) Model 2. Data from the qualitative explorative pilot study built on to the existing knowledge from Model 1.

(iii) Model 3. This Model included both the main study and the ASPIRE data. This data was combined with Models 1 and 2, to fully develop the model. Model 3 led to the outcomes: policy and health service implications, and an assessment decisional tool. ASPIRE data was included to increase the robustness of the study, and to add other perspectives which could not have been gained by OPERA alone.

6.1: Model 1

The literature review highlighted many specific areas of previous study, including the risk factors for residential care entry (A. Bebbington et al., 1995). The predisposing triggers for residential care entry, decision-makers and the satisfaction of caregivers with the final residency of the older person, were also reviewed in articles (Freedman, 1996; Miller & Weissert, 2000). There were no articles found which collated all the areas such as factors, decision-makers, or the subsequent older person satisfaction. Nor were any articles found which compared quantitative and qualitative data to give a perspective of the significance of the decision-makers, the influencing factors, and the satisfaction of not only the caregiver, but also the older person.

The two most commonly reported risk factors for residential care entry were: advanced age; and the older person having difficulty with daily living functions (Table 6.1). Other risk factors listed were: the inability of the caregiver to continue to provide adequate support; the older person living alone; and the older person being of European descent (described in the literature as ‘White’). Co-morbidity and the older person having dementia were valid risks, but less often mentioned in articles. Table 6.2 lists the risk factors from the literature under the three categories used by many authors, as a demonstration of the diversity of risks. The placement of the risks within each category was the authors' choice. The first category was ‘predisposing’ which describes the risks which were mainly demographic or dealt with social support). The ‘enabling’ category was less well used, but described factors which affected the decision-maker and residential resources. These could apply to home or residential care. The last category ‘need’ identified the older person’s vulnerability, which was mainly in the areas of their disabilities. Authors have not been consistent with their use of categories, consequently some of the risks have been classified under more than one heading.

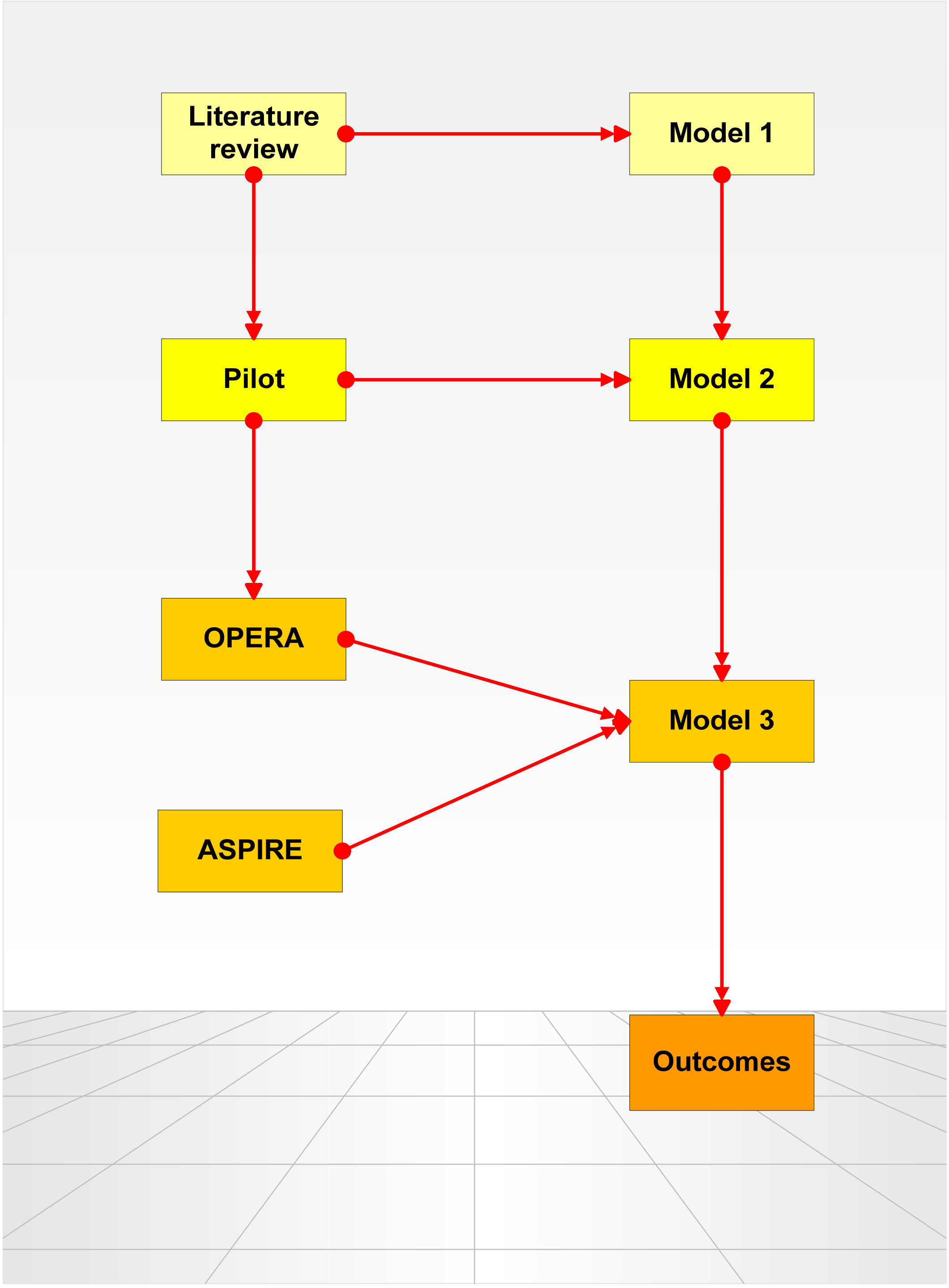


Figure 6.1: Development of the model for risk of residential care entry

The use of the categories did lend itself to some anomalies, for example, being male (Bauer, 1996) and being female (Liu & Tinker, 2001), were both listed under ‘ predisposing’ as being indicative of residential care entry from different articles.

Table 6.1: Most common risk factors appearing in journal articles

Risk factors	**Number of articles**	**Risk factors** **Number of articles**	
Age	20	Worried about health	7
Difficulty with daily functions	20	Being female	6
Living alone	13	Financially poor	6
Caregiver not coping	13	Incontinent	5
Being of European descent	11	Poor mobility	4
Co-morbidity	10	Cognition problems	4
Dementia	9	Being male	3
Previous hospital admissions	7	Rest home availability	3

Figure 6.2 developed from the literature review and shows the progress of the older person after an event which changed their support needs. The process started with an assessment of the older person’s capabilities and support requirements. Risk factors interacted and led to a decision regarding the older person’s safety while living at home. Predictors, which were events that frequently led to the older person entering residential care, were also involved. The factors could also be predictors, but were more often seen as a reason for the residential care entry. Any or all of three categories of people: the health professionals, the family and the older person could be responsible for making the decision about the older person’s permanent residency (home or rest home).

Table 6.2: Risk factors for residential care entry demonstrating the three categories

Predisposing factors	**Enabling factors**	**Need factors**
Aged over 80	Poor informal home care	Functional impairment
Living alone	High rest home availability	Daily function difficulties
Being of European descent	Cerebrovascular accidents	Cognitive dysfunction
Daily function difficulties	Poor supply of paid services	Dementia
Caregiver not coping	Urban dwelling	Carer problems
Being female		Incontinence
Worried about own health		Self-rated poor health
Co-morbidity		Prior hospital admission
Prior hospital admissions		Musculoskeletal problems
Dementia		Disorientation
Poor mobility		Cerebrovascular accidents
Poor financial resources		Respiratory disease
Cognitive dysfunction		Poor vision
Being male		Hearing loss
Decreased motor function		
Incontinence		
Depression		

6.2: Model 2: Pilot

The description of the pilot study, which was structured under major themes, involves figures, tables and narrative, illustrated by quotations. The pilot developed the ‘risk’ model by exploring the decision-making process after an older person was assessed as needing higher levels of support. The reasons for the change of support were for the safety of the older person, and/or to provide more assistance for their caregiver. Each older person described what they remembered or understood about the processes, decision-making and the reasons why they were living in either residential care or their own homes. To gain an understanding of the process from the health professionals’ point of view, it was necessary to interview the Needs Assessment Service Co-ordination managers (NASC) and the Multi-disciplinary hospital team (MDT). The results of this pilot gave a basis for the development of the main study questionnaire.

All the interviews were analysed and collated to form three themes. The first was 'changes', which described the triggers for the review of the existing support needs for the older person. Secondly, 'control' referred to the person who made the decision about the where the older person was considered safe to live (residence). Finally, 'placement' described some thoughts about the older person's residence, either in residential care or their own home.

Changes theme.

There were two types of changes which could have occurred to the older person to initiate a reassessment of their support needs: (i) events which were of sudden onset, for example a cerebrovascular accident, fracture, heart attack, death of a spouse, or loss of a caregiver; and (ii) deterioration of an existing condition, such as Parkinson's disease or dementia. There was some difficulty in restricting the changes to one particular category as many were overlapping; however, they were grouped into the most appropriate categories, as shown in Model 2 in Figure 6.3.

The category 'family limits' was typical of a spouse who was no longer able to look after their partner, or a child with too little time to cope with the needs of their parents. 'Social implications' described support at home and how that impinged on the abilities of the older person and their caregiver. The comments of Mrs B's spouse illustrate both these categories:

> *Primarily the problems were getting worse. We tried getting help in and it just wasn't working, partly because of the nature of the house……so they decided that I could get relief from* [his wife] *by her going into a rest home.* (M.B.spouse)

'Physical impairments' described the conditions or disabilities of the older person, including a recent cerebrovascular accident or fracture, but also included the frail elderly who were no longer able to look after themselves. One man, describing his falls, said:

> *I had about three falls and they put me in hospital….then they said I had Parkinson's disease.* (N.McK.)

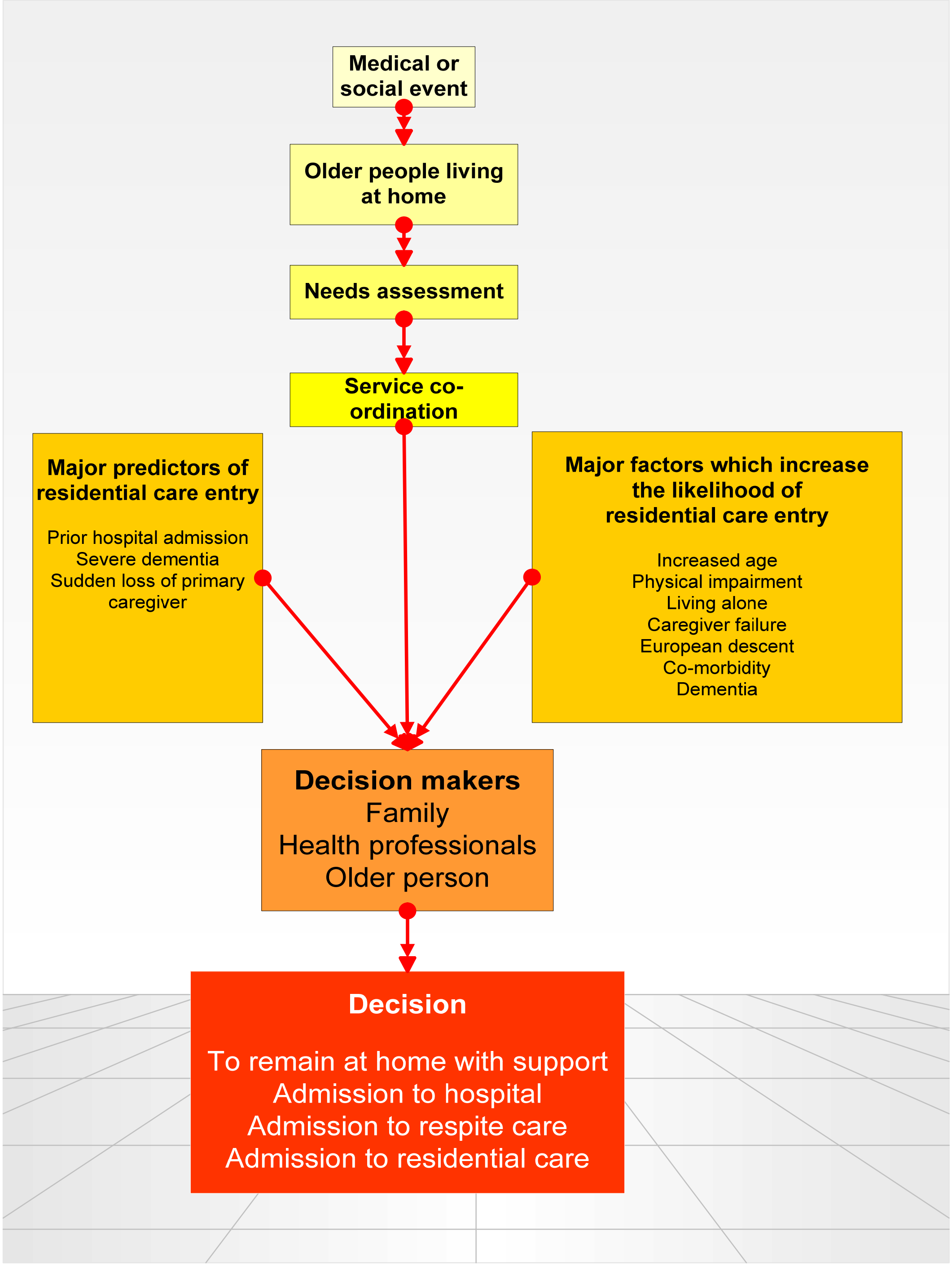


Figure 6.2: Development of Model 1 from the literature review

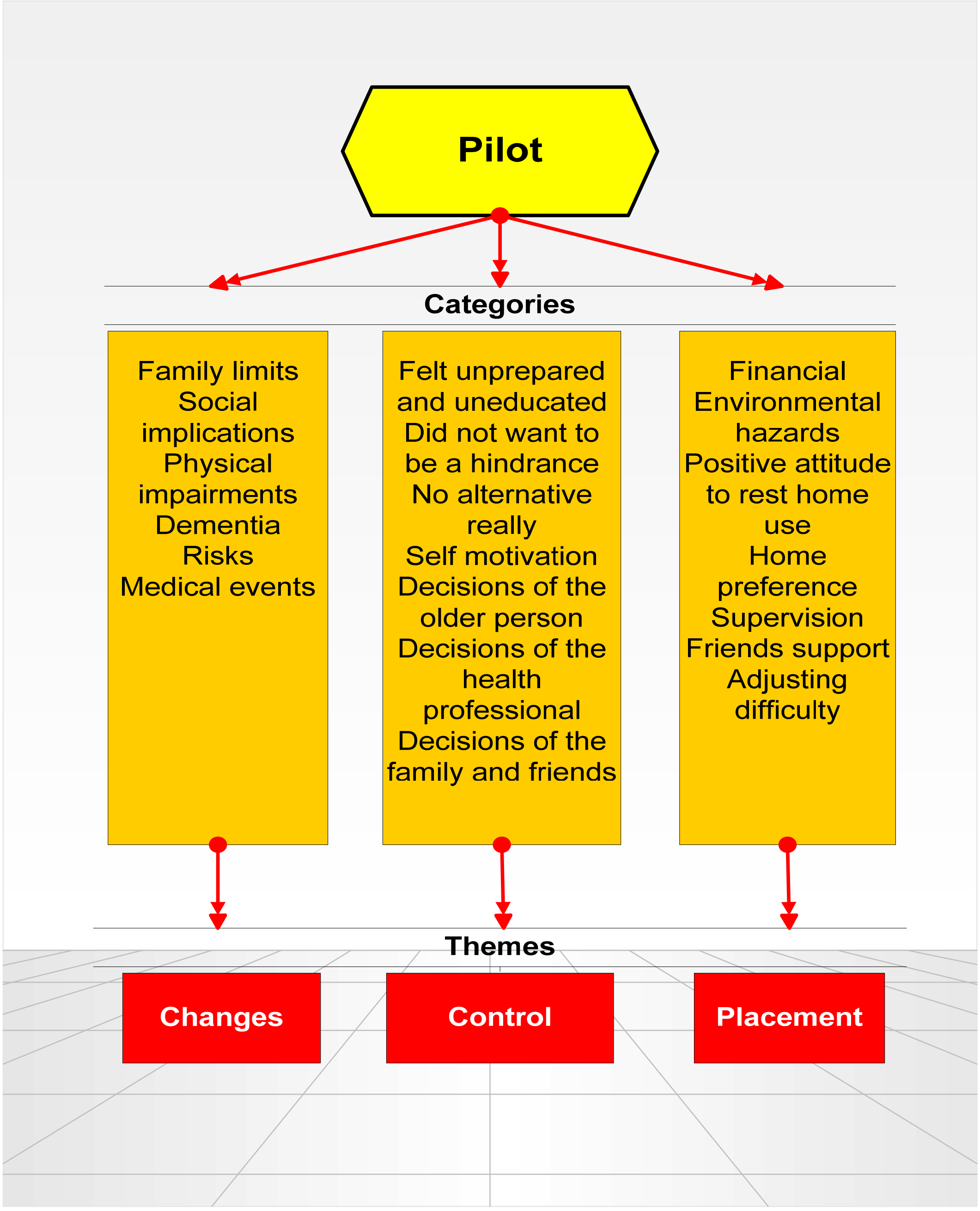


Figure 6.3: Themes in Model 2: Pilot

Some people who were in the ‘dementia’ category managed well at home with support, but for others this became too difficult for the older person and the caregiver. The ‘risk’ category included older people who were at risk from falling, or felt fearful of being home alone. One husband who was managing risk and his wife’s dementia said:

> *The only things that would put* [his wife] *in a* [rest] *home would be her walking and her memory. She couldn’t live on her own unless you got a person to live in nearly 24 hours of the day. That is of course if I dropped down dead.* (B.A. husband)

‘Medical events’ category was any event which left the older person unable to cope with the existing support, such as an operation, amputation, or chronic pulmonary or cardiac disease. A son explained the reasons for his father going into a rest home:

> *When he went into hospital for the amputation of his leg the doctor suggested that we find him a rest home. We could not continue to look after him at* [his] *home and did not want him to live in our home.* (E.P. son)

A sudden (triggering) event was found to have led to the need for an assessment and reclassification of the support needs of 10 older people within the pilot. Prior to this, all the older people were living at home with satisfactory support from others. These events led to a hospital admission, but varied in nature, with the most common cause being a cerebrovascular accident, and the most common disability being decreased mobility. Three other older people were reassessed because of deterioration in their existing condition, which in all cases was dementia. The Pilot characteristics are shown in Table 6.3.

Prior to discharge from hospital, or after it was recognised that there was a question of safety in the home, an assessment was undertaken by the MDT. This was necessary to assess the older person’s level of functioning, and the support needed to ensure their safety. All 13 older people in the pilot were categorised as needing high or very high levels of support, which led to a referral to the NASC to organised suitable help. This included either more support at home from paid caregivers, or residential care.

Table 6.3: Pilot participants' characteristics (N=13)

Type	**Description**	**n**
Gender	Female	9
Hospital admissions	Within the last year	9
Residence	Residential care	7
	Home	6
Primary diagnosis	Cerebrovascular accident	5
	Dementia	3
	Fracture	1
	Amputation and other	4
Disability	Decreased mobility	8
	Confusion	3
	Frail	2
Decision-maker	Geriatrician	4
	General practitioner	3
	Multi disciplinary team	2
	Family	2
	Older person	2

Control

This theme refers to the person, or group of people who made the decision about the permanent residence of the older person. The people making up the 'decision-maker' category were the older person, the health professional including the doctors, family and friends. Deciding who had the control of the decision was difficult because all parties, except for the older person, thought that the older person had the control. It was clear from the MDT and the NASC that they considered they had consulted with the older person and their family.

The older person was asked to describe the decision-making process, and who they thought had made the decision about where they were to live (residence). Residence in this study referred to a place, either home or rest home, where the person was living permanently. Some older people thought the decision might have been spoken about, but could not understand the discussion due to their hearing, or the medical jargon. In most cases, when the older person was in hospital, they remembered a doctor talking about what they could not do, either directly to them, or to other medical people near them. It appeared to be a one-way conversation, which led to the older person's general frustration about communication and understanding. Some thought that the medical team had a meeting prior to talking with them. Only two older people felt they had influenced the decision. Several older people said the doctors and nurses were so busy that they did not have time to listen. Others said they had not understood what was being offered in the way of services, or even what the choices of placement were. One caregiver illustrated this point by saying:

> *The services were offered, not explained, he did not know what they were and did not want to sound stupid by asking. He did not understand the language; they spoke in medical-speak, not plain words ….Professional services seem to take all that away when they talk to people. They give the person no choices….The process to know everything is very long and fraught with difficulty; it is like a snake pit.* (T.S. niece)

The MDT's role in the decision process was to assess the older person in order to determine what support they needed, and how this could be met, whereas the NASC assisted the older person or the family by accessing the support needed, including 24-hour support such as residential care. The residence decision was one predominantly made by the health professionals, which included the geriatrician, general practitioner and MDT. Seven out of the 13 older people cited doctors as the people who made their residence decision, and two others cited the MDT, which would have included a doctor. When asked about the decision process, one lady quoted the doctor as saying:

> *I really think that you need to be in a* [rest] *home to look after you. You are not walking properly and you would have to get a ramp made so that you could get up the steps* [at home] *and that.* (N.P.)

In most cases the older person had become resigned to the decision made for them, but there was one notable exception. A lady, post cerebrovascular accident with dysphasia (language difficulty), asked the MDT on their weekly ward round if she could go home. She said:

> *I managed to say to the doctor 'go home' and pointed to myself and he laughed at me and said you will never be able to go anywhere from here; you will go to a rest home.…The doctor then said if you can walk from your bed to the door then you can go home. My friend grabbed hold of my feet and slowly stood me up ...it took a whole day, but I got to the door.* (N.KW)

She self-discharged later that day and is now living with support in her own home.

The 'felt unprepared and uneducated' category was about communication and how the information was portrayed to the older person. This feeling was evident to some degree in most of the interviews. Mrs M described her feelings as: *"Some girls promised me all these things, but I didn't take everything in*" (M.M.), and a caregiver commented: *"His preference is to stay at home. He was unable to understand all the information given to him by the doctor".* (T.S. niece)

The 'motivation' category included not understanding or knowing the choices. This led to an apathy in some people, while in others it was a feeling that nothing more could be done for them. Some people were not able to access more support and didn't know where to turn in order to satisfy their perceived support needs*: "I just lost interest in looking after myself then"* (H.G.). There were also a few who were determined and motivated to improved their situation and do their utmost to remain at home:

> *If by some chance that I ended up not being able to walk, I would get a motorised wheelchair and I would make sure that my house was modified for me.* (N.KW.)

‘No alternatives really’; again this category had a lot to do with communication and knowing what support was available within the community. The question asked of the older people was, ‘If all the support you need was provided in the community where would you rather live?’ Nine out of the 13 people said they would like to stay at home. One person felt she had to go into a rest home because she didn’t want to encumber her family. She knew of no other alternatives to rest home:

> *Well there is no alternative really unless the family come into it. I am one of seven but it is my sister really, you can’t go and live with them you know, they have their lives to live and that is what I mean about alternatives.* (J.L.)

‘Didn’t want to be a hindrance’ was a category which described the feeling of powerlessness and causing bother or concern to others. Options were not communicated in many cases, so there was a feeling of powerlessness, and consequently a feeling of being a bother. It described people who didn’t ask questions, and just accepted the status quo, even to their own disadvantage. Usually it was not wanting to bother the family, but in the following example it was not wanting to be a bother to the general practitioner: *"He is a proud man and didn’t want to be a hindrance and still wants to be considered useful".* (T.S.niece)

Placement

Placement or permanent residence after an assessment for a change in support was one of two options. The first was for the older person to stay in their home in the community, with paid support, or increased support from family or friends. The second option was to be placed in residential care, either as a continuing care hospital resident or a rest home resident, depending on the older person’s support needs. Placement in residential care became the viable option when there was no spouse, no family living within close proximity, insufficient community support from friends or other caregivers, or little financial resources to make changes. Most people admitted that they did not have neighbours who were willing to assist with their personal care.

Residential care was never talked of as 'home' by the older people, but rather as the place where they 'had to be' to get the assistance they needed. While most were resigned to being in residential care, three older people were much happier there than they had been at home. Those who were living at home were in the main happy, although one lady was worried about her support if her son moved. Several people did have children or grandchildren who were looking in on them, and in one case cooking for them, but this became difficult when families were unable to visit often. Cost was a perceived barrier to residential care, as pointed out by the following comment:

> *He was scared about* [residential care] *costs, so he just said he was fine, he would stay at home, but he is not fine.* (T.S's niece)

The MDT also saw cost as a barrier to managing the older person at home:

> *The cost of that* [looking after the older person at home] *is high also. They have to be driven to the doctor and to get medicines etc. If a person stays at home to look after their parent they do not get much financial support.* (MDT)

Placement was the culmination of a series of events leading to a decision about where the older person would reside. The flow chart (Figure 6.4) illustrates the journey from the event, which precipitated the older person's support needs assessment and re-categorisation, to needing the level of support consistent with residential care entry, to their permanent residence; in some cases, back to another event which started the circular process all over again. If the older person or their caregiver was at risk, the general practitioner or hospital doctor referred the older person to the MDT and/or MDT services. Around this time a decision was made

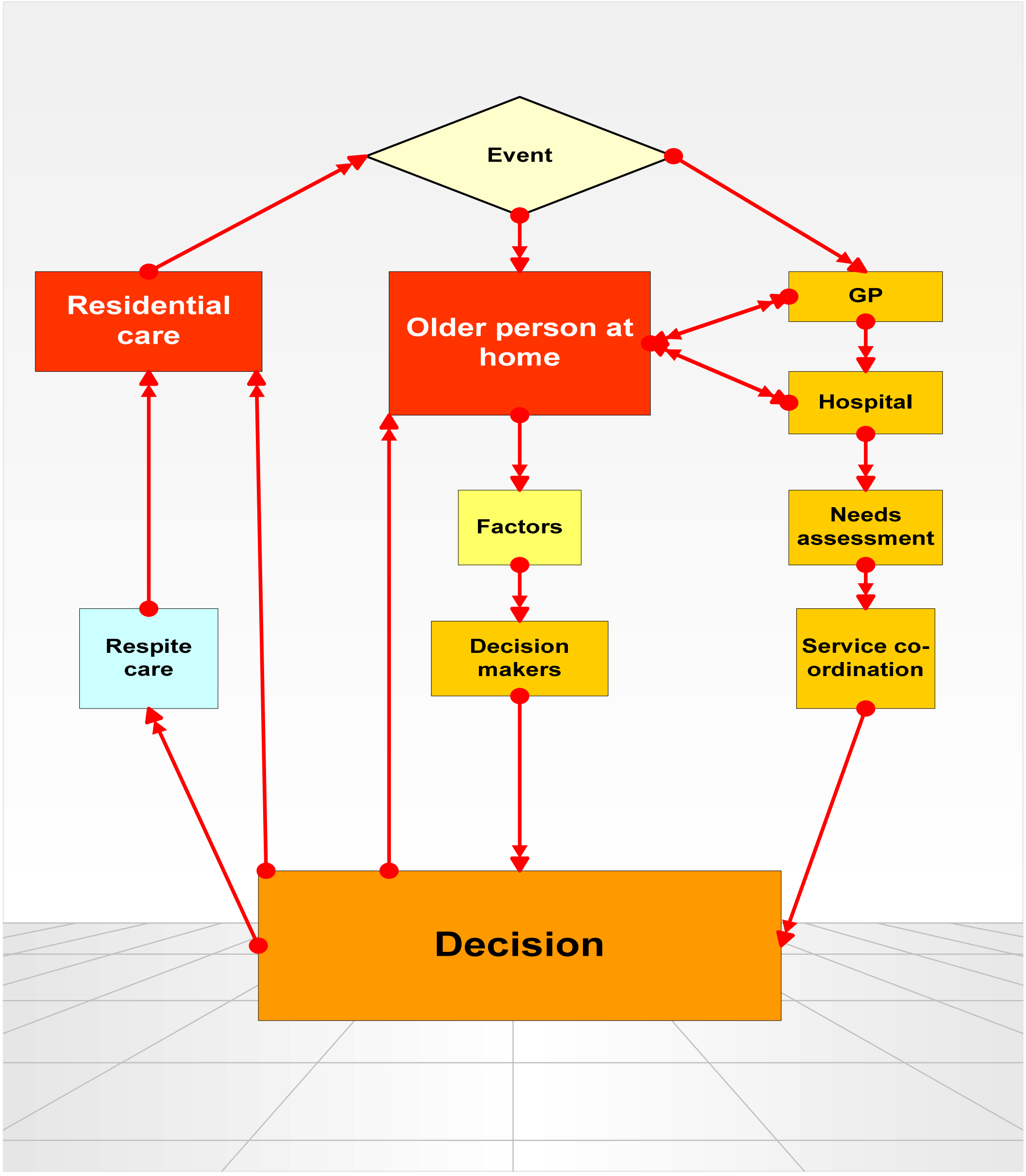


Figure 6.4: Flow chart from the older person's event

about the safest place for the older person to live. This could have been in a temporary situation, such as respite care, a return home with sufficient support services in place, or the 24-hour support of residential care.

6.3: Main OPERA study: Model 3

The findings from this Model were structured under major themes, and have been presented as a narrative illustrated by quotations, figures and tables. A sequential model of the themes progression from the initial event to the older person's permanent residence is shown in Figure 6.5. How the older person or their caregiver was coping with their living situations was pivotal to the start of the sequence. The next step was the adequacy and quality of the support, which enabled the older person and caregiver to manage in their home. Decisions surrounding how best to maintain the older person, or their caregiver's safety, were prompted when some event changed the equilibrium and safety was compromised. Finally, a residence was chosen which was deemed suitable for the older person and caregiver (where appropriate) to live safely with adequate support. In order to isolate the themes, major codes were developed from the interviews and organised under categories which then led to the four themes in Model 3.

Coping theme

> *I am an old soldier and I have learnt how to survive, you have to really don't you.* (R.A.W.)

Coping was the way a person managed their situation, their disabilities, and the outside forces which interacted with them. The situations with which an older person was coping were diverse, and ranged from any of the multitude of medical conditions to the more intangible issues such as feelings. For clarification, coping has been divided into two main subheadings: (a) physical issues, and (b) emotional issues (Figure 6.7).

(a) Physical issues. A major part of coping was dealing with health concerns. This was expressed by the older people in both a general and more specific manner such as: *"I feel my health is getting worse and soon I will have to go into a rest home"* (M.J.P); and more specifically:

> *It is difficult for me now that my eyesight is so bad. I get letters from my daughter and I can't read them. I open the letter and kiss it and then wait for my son to come and read it for me.* (H.E.S.)

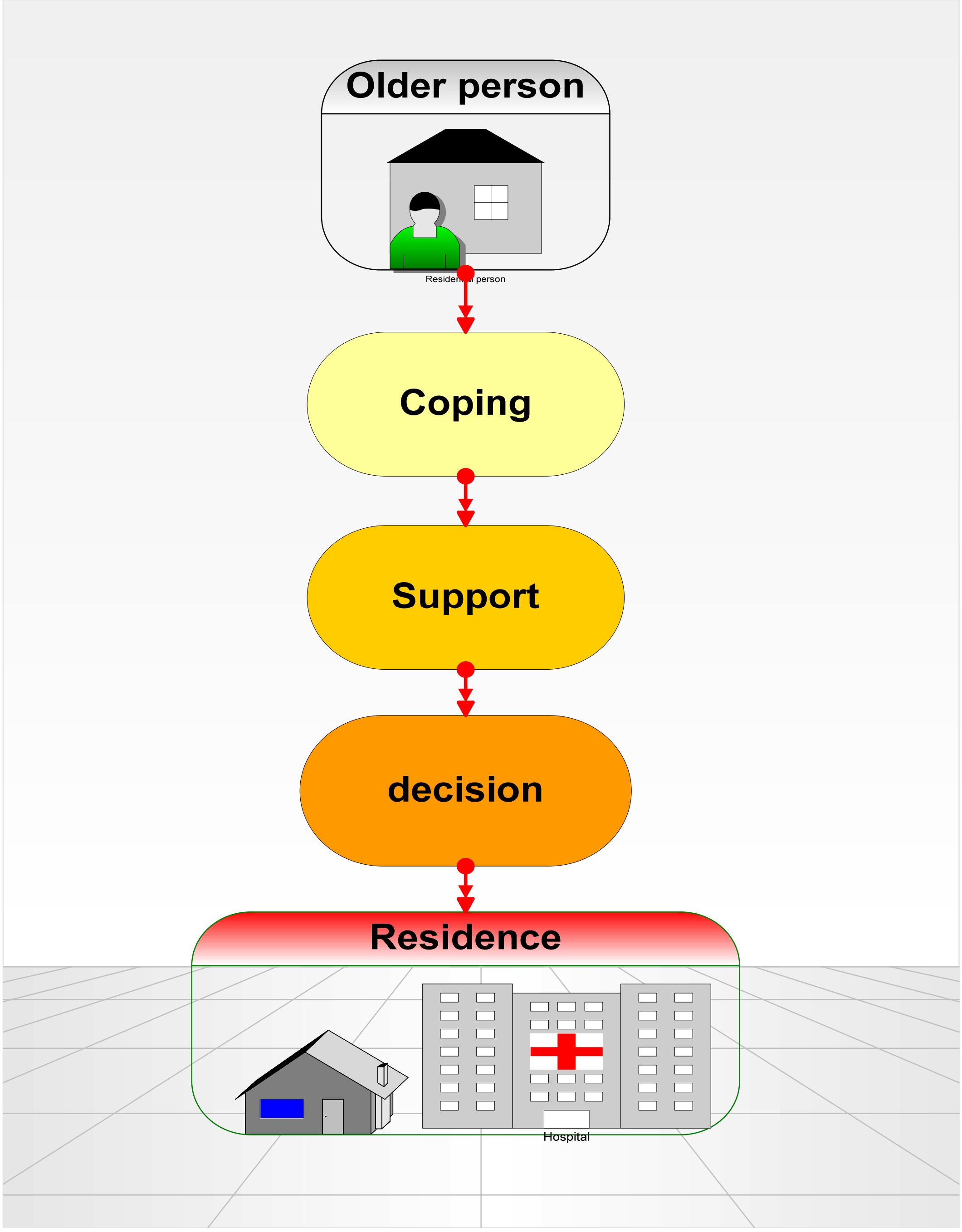


Figure 6.5: Model 3: Sequential progression to permanent residence

The ‘mobility’ code encompassed the ability to move from one place to another, and be able to get to basic areas within the house, such as the toilet or kitchen. Outside the house, it was the ability to clear the mailbox or go to the local shops which caused frustration.

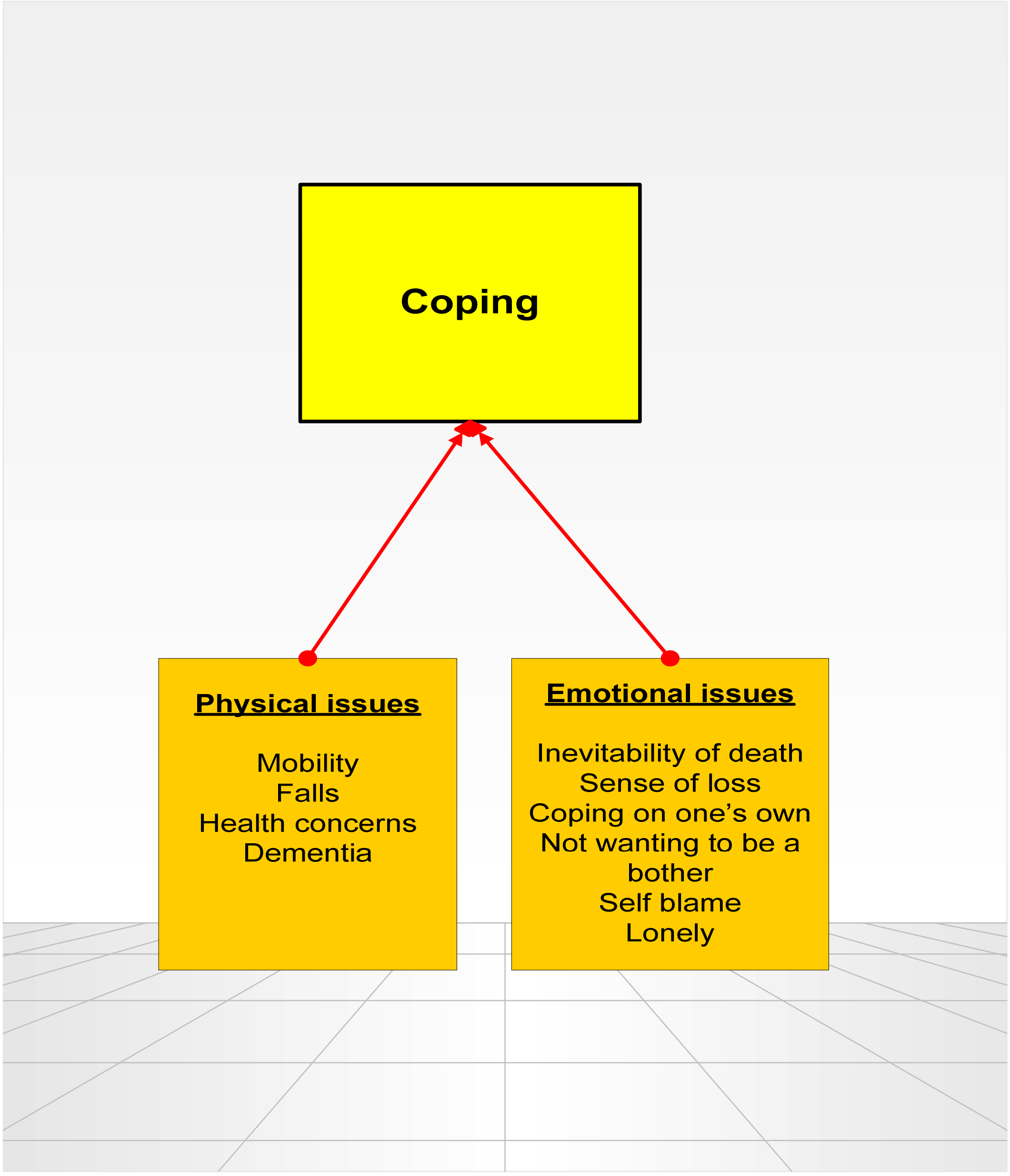


Figure 6.7: Codes which make up the coping theme

Many people coped with walking frames, sticks, scooters, or just someone near ‘in case,’ however, the overriding comments were that they would like to ‘get around a bit faster’. In some cases it was the family’s concern about the mobility and subsequent falls which predetermined residential care entry:

> *The family wanted me to go in here* [residential care]*…they thought that I would fall; they have always had that fear that I would fall and no one would hear and I would be left there.* (M.F.)

Two other significant factors which older people had to cope with were ‘dementia’ and ‘incontinence’. The former was mentioned most often by the spouse and usually in relation to having to move in the future due to not being able to manage, as illustrated:

> *We do not want to move, my wife has dementia and I look after her, but we will stay here for as long as we can.* (A.H.)

Incontinence was a complaint of many of the older people, but most were coping with it by using pads, or other devices. One spouse commented that they had been together for 49 years and had never had an argument, but incontinence was causing a problem:

> *They suggested that I move into a single bed but I couldn’t sleep without him. He has accidents wetting.* (R.J.G. caregiver)

Another person living in a retirement village related the reasons for her being in residential care as:

> *The nurse from the rest home came over to my unit and said that since I was incontinent that I should not be here; I should be in the rest home. I was not able to look after myself when I was incontinent.* (N.M.T.)

Many of the older people with more than one problem were able to live at home with the support they received:

> *I have only two problems my diabetes and my incontinence, but they are being managed quite well* [at home]. (F.J.P)

Other areas where the older person was coping were not as overt, and often not noticed by others.

(b) Emotional issues. The over-riding feeling among the older people was a sense of loss. Broadly, loss could be subdivided into three parts; (i) missing their home, which included family, friends, animals and gardens. This was caused by their relocation to a smaller more practical house, being moved in with family or going to residential care. Sometimes it was because friends had died or moved away; (ii) the loss of their spouse, usually after many decades of living together; (iii) missing their youth and the way they 'used to be,' or for lost opportunities.

One rest home resident commented about the loss of her cats and a feeling of being homesick:

> *I would have liked to continue in my own home. It still makes me sad when I think about it. One of the saddest things was that I had to leave my cats. I had two lovely cats …they took my cats away from me, I don't know what has happened to them, and I don't like to ask. They were really my family. There are no cats in here; I do so much miss them. I am still sad about all this and in here I get no sun in my room and just sit here all day …I guess you could say I am home sick.* (E.M.T.)

Another person said:

> *We have been married 60 years and this is the only time we have been apart. I am sad about it. I would like us to have a room together in the rest home. He is in a different part from me.* (J.E.)

Lost youth, or to be young again, came up fairly frequently in conversations with comments such as: [I would like] "*to be young again, there is no joy in growing old.*" (G.H.H.)

Loneliness was another of the emotional issues which was found both at home, and within the rest homes. At home it was the lack of family and friends, or not having the opportunities to get out and mix with others. In some cases relocation placed people outside the area where their friends could travel to visit them. At times family would move the older person to be nearer to them, and in doing so dislocated them from their previous peer group. While families offered support to the older person, there were plenty of hours in the day and night where the older person had the potential to be lonely. Families were invariably busy with jobs, children and social activities. In the rest home it was often a feeling of isolation within a sea of people. People were isolated in their rooms either voluntarily or involuntarily, or isolated within a group due to an inability to communicate. One person living in a rest home commented:

> *I wish that I had died when I had my last stroke. I don't have any friends here in this place. I sit at the table with five others and none of them speak. Two are deaf, one just answers in monosyllables and the other sleeps all the time. I just stay in my room and watch television because there is little else that I can do when I have no friends.* (J.L.E.)

Another lady who was moved nearer to her family chose to move back to her home town to be near her friends. She talked about the place where her son had moved her to be nearer to them:

> *I lived upstairs in their house and they were good to me. I had nothing to do except to wander around and look at the gardens, and you can't do that all the time. One day I said that I wanted to go back to* [city], *because I was away from my friends. I came here* [city] *to live when I was married, and so my son brought me back.* (E.E.S.)

A feeling of impending death led to a lack of desire and to just accepting the inevitable closure to their lives. This was the feeling of a few of the more incapacitated people, and also some who appeared lonely and unstimulated. There were comments from the older people such as: "*I won't be here much longer*" (R.McL.); "*now I see no future for myself and would like to just fade out*" (R.B.); and "*there is nothing to live for anymore, so I have just given up really*" (B.S.).

While self-blame such as "it is my own fault if I can't manage" was infrequently heard, "not wanting to be a burden" was more common, and at times the reason for residential care entry. In one case the person did not want to bother the family now, because she hadn't gone into residential care as they advised. Another person did move into residential care to avoid being too much of a bother to the family, as demonstrated by the following conversations:

> *I found that I was relying too much on my family to do things for me, so I thought that it was time for me to make a move. So that is why I came in really.* (M.G.)

and

> *It was also the worry about my family doing too much that made me come in here* [residential care]. (N.M.T.)

Coping had a lot to do with adequate support, and a good feeling of self-efficacy in a supportive environment. The next progression from the coping theme was the support theme, how it was managed, its appropriateness and what form of permanent residence became necessary.

Support

Support was the assistance given to the older person which enabled them to live within a safe and hopefully fulfilling environment. Support could involve personal support, such as assistance with bathing, and physical support, such as exercises and walking. The two other types of support were emotional support, which could be given from a spouse, family or friends, and environmental support, such as the provision of chair raises and ramps. This theme has been divided into two support categories (a) ‘family and friends,’ and (b) ‘community support services’, which was basically the division between the funded and non-funded support (Figure 6.8).

(i) The ‘family and friends’ category describes how the older person felt about the support from their family, and any problems which might have been incurred with or by the family. The most frequently mentioned family caregivers were the daughter, and less often the son, and grandchildren. Although some older people had a spouse, it was seldom that they referred to them as caregivers. Comments similar to this were frequently heard:

> *Yes we have three daughters who all live within a few minutes of us. Two help in the house and they are wonderful I have an excellent relationship with them. We are so lucky.* (I.D.S.)

When sons were mentioned it was most often in relation to finances or gardening, while the daughters were the shoppers, cooks, and at times cleaners. The daughters also did most of the organising, as described below:

> *I don’t know too much about it* [community support services]. *I have always helped others. Yes I know about district nursing and home help through my daughter who is a nurse in a rest home. She organises everything for me.* (R.A.W.)

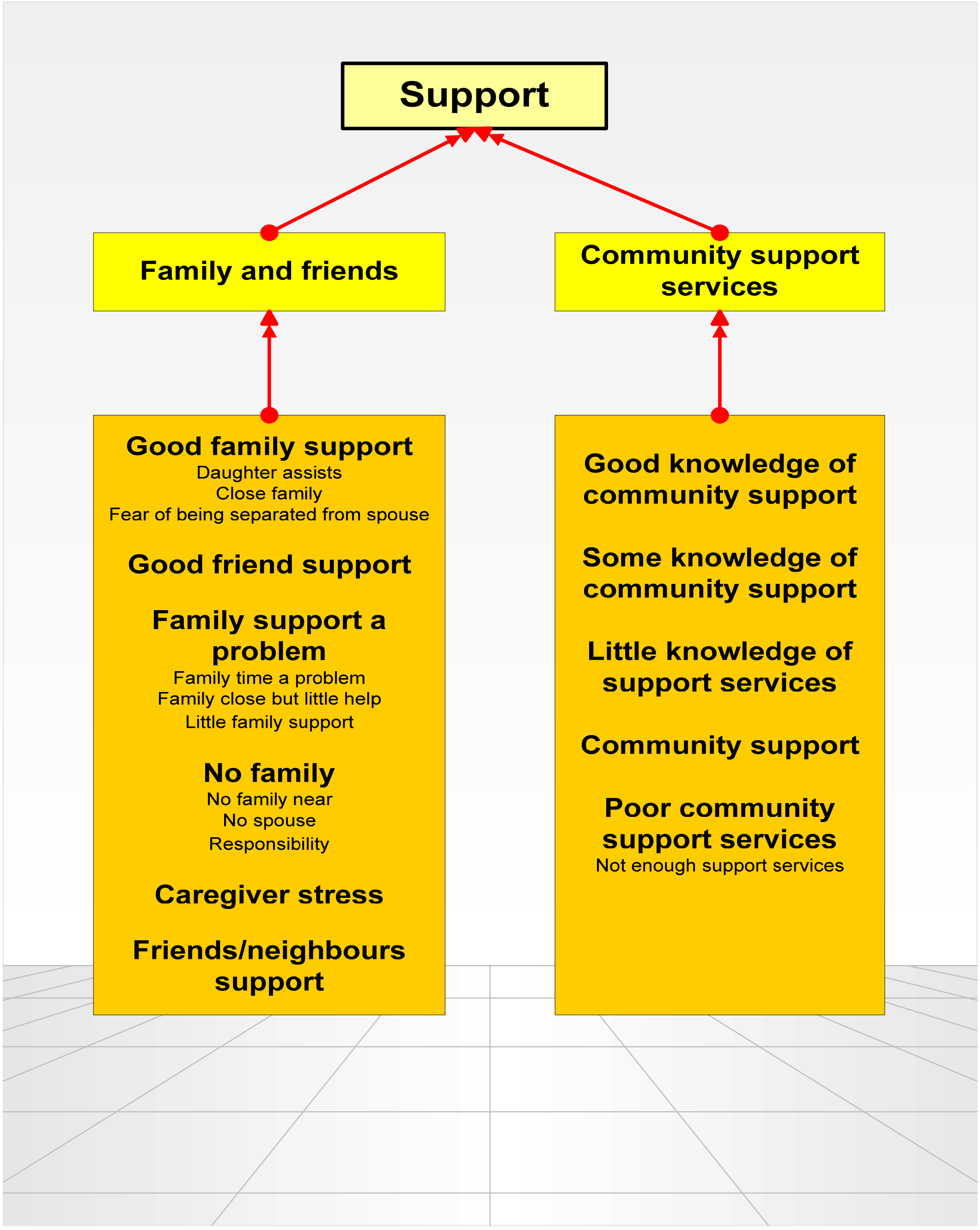


Figure 6.8: Codes and categories which make up the support theme

One lady was worried about being separated from her husband and said that if he went into a rest home she would go in too. Many of the people who had spouses had been living with them for upwards of 40 years, and a separation either by death or residential care after that length of time was clearly difficult. M.J.W. illustrates the point:

> *I would like my husband back. You see we were married for 52 years and then he had a sudden cancer and died four years ago and I still miss him.* (M.J.W.)

Children being busy with their own family, or work and not having much time, were constant comments. Because they were busy, the older people hesitated to bother them. One lady said that because her daughter was now widowed she had to work full-time and could no longer help her. Due to this she felt that it was probably time for her to go to a rest home. Some older people did not feel close to their children and did not get much assistance from them. There were also some who lived close to their children, but had little or no contact with them. One older person reported that her daughter said:

> *I didn't leave nursing to turn around and look after elderly people again, not even my own mother.* [The older lady then said:] *That stung a bit you know.* (H.E.S.)

Friends and neighbours seem to fill in the gaps in a few cases. One lady (G.H.H. 98148) had an arrangement with a man to take her shopping. She gave him her car when she lost her licence, with the understanding that he could have it if he took her shopping once a week. This arrangement worked well for her.

Primary caregivers (voluntary) played a major part in the lives of many of the older people. The caregivers were mainly spouses, partners, children, with a smaller number of siblings and other relatives also assisting. In many cases the caregivers were managing with extra support when needed, and there was caregiver stress evident in some situations. Part of the stress with the caregivers other than spouses was the time factor with children, jobs, and other commitments which had to be juggled throughout each day. Other stress was the lack of outside support that the caregivers were able to access, although in some cases the older person did not want help, other than the spouse. Mr J.D. refused more help and refused residential care entry, even though his wife admitted struggling to cope. Some spouses or children were themselves not well, which increased the stress levels. The NASC described one older person who entered residential care because of caregiver stress as follows:

> *She was categorised at hospital level care. She had home help and daily assistance. Her husband called us to say that he was unable to manage her any more, so he suggested rest home.* (E.J. NASC)

The amount of care needed to be given and able to be given by the caregiver varied enormously. This was either due to the caregiver's own frailty, or the other time commitments they had. The weight of responsibility for the care was something that a few people mentioned, such as not often being free to go out, or wondering if their relative would be adequately looked after without them. One person commented:

> *Even while I am at work I am worried that perhaps the* [paid] *carer won't come and I will have to come home from work.* (G.E.A. caregiver)

Caregivers in some cases felt that no matter what the sacrifice, the home was where the older person should be, and as long as they were able to, they would continue to look after them. One spouse commented that if he wasn't there then his wife would have to go into a home; which was typical of many others in similar circumstances.

(ii) Community support services

> *Older people with high and complex health and disability support needs will have access to flexible, timely and co-ordinated services*

> *and living options that take account of family and whanau carer needs.* (Ministry of Health, 2002b, p. 77)

Most of the older people in the study who were living at home were accessing some form of community support to assist with their day-to-day tasks. The support ranged from the complex district nursing tasks to the loaning of equipment. Most of the support was help with housework and personal care, such as showering. The comments about the services varied greatly. Some people were really happy with the home service, for example, that the Nurse Maude organisation (Christchurch) provided, and said they would find everything for them. Others were frustrated and said it was really hard to get to know what was available, and then really hard to get it, get it organised, and finally get it running smoothly. A common complaint was no service during the holidays, weekends, or when their usual support services person was sick. Others complained that there was just not enough help to prevent the older person going into rest home care, as shown in the following statement:

> *He has gone into care now. The doctors suggested it…I was getting to a point where I couldn't manage by myself and he understood that too. There was not enough help at home to manage any more. I cry every night when I drive home from work because I am coming home to an empty house. It was a real shock, but there was no other option.* (J.F. caregiver)

One of the questions asked of both the caregivers and the older person was whether they knew what community services were available, and if they knew how to access them. Most had limited knowledge, but did know about district nursing and home help. Most also knew that help could be accessed through their general practitioner, or local hospital. Those who did not know how to access the services relied on someone else, usually their daughter, to inform them. There were very few who knew nothing about the services and had no assistance, such as family, to source the information for them. However, in general the information that people had about services was limited and many people said they really didn't know how much, or specifically what, they could get. They thought they were just given what the agency thought they needed.

Decisions

At some stage after an event which caused the older person to be reassessed for their level of support-needs, a decision was made about the safety of the older person to live within their own home. The decision theme describes who made the decisions about the permanent residence of the older person. The words decision and decision-maker in this chapter refer solely to the decision about where the older person would live after they had been assessed for the level of support they needed. The older person, caregivers and the MDT staff were given the option of selecting as decision-makers any number of the following: the older person, family, hospital doctor, general practitioner, hospital nurse, social worker, friends, district nurse, practice nurse, physiotherapist, occupational therapist, and the NASC. Only the first four had significant numbers, with the others having less than 1 percent stating that they had made a significant influence in the decision-making. The place where they would live was combined into two groups, (i) residential care, including rest homes and continuing care hospital, and (ii) home, or all the other places where an older person might choose to live and call home, including retirement village, and a family member's home.

The person who had the major influence in the decision could have been one of three groups: the older person, the family, or the doctor (which includes both the general practitioner and hospital doctors). Table 6.4 demonstrates that the majority (86%) of the older people felt they had the power to decide to either remain at home or enter residential care. A lesser number of older people thought that their family was involved in that decision (47%); however, the reverse was seen in the caregiver's report, (Table 6.5) and NASC report (Table 6.6). In the caregivers report most (92%) stated that the family made up the majority of the decision-makers. A larger percentage of family as decision-makers was also reported by the NASC (Table 6.6) at 84 percent. Both the NASC and caregivers gave lower numbers for the older person's influence. Overall the majority of the decision-makers were the older person and their family; the hospital doctor and the general practitioner were the next most commonly noted decision-maker. In the NASC report, the hospital doctors featured more highly than the older person (42%), while the caregiver's and older person's reports noted the hospital doctor's influence at 13 percent and 15 percent respectively.

Table 6.4: Older people's report on decision-makers (N=131)

	Older person		Family		Hospital doctor		General practitioner	
Influence	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Strong	**113**	**86**	**62**	**47**	**19**	**15**	**11**	**8**
Some	**8**	**6**	**8**	**6**	**7**	**5**	**5**	**4**
Little	**10**	**8**	**61**	**47**	**105**	**81**	**115**	**88**

Table 6.5: Caregivers' report on decision-makers (N=24)

	Older person		Family		Hospital doctor		General practitioner	
Influence	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Strong	**12**	**51**	**22**	**92**	**3**	**13**	**0**	**0**
Some	**8**	**33**	**0**	**0**	**2**	**8**	**4**	**17**
Little	**4**	**16**	**2**	**8**	**19**	**79**	**20**	**83**

Table 6.6: NASC's report on decision-makers (N=12)

	Older person		Family		Hospital doctor		General practitioner	
Influence	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Strong	**4**	**34**	**10**	**84**	**5**	**42**	**3**	**26**
Some	**2**	**16**	**0**	**0**	**1**	**8**	**2**	**16**
Little	**6**	**50**	**2**	**16**	**6**	**50**	**7**	**58**

NASC = Needs Assessment Service Co-ordination

There were many variations to the way decisions were made, but in one more unusual case it was a decision primarily by the older person against the family, but with the aid of the general practitioner, as described:

> *My daughter arranged for me to go into a rest home and said that I had to. I said that I wouldn't and didn't see that she could make me. She was most insistent. I then talked to my general practitioner about it and he said 'do you want to go in?' and when I said no, he said 'then don't.' So I haven't and I won't.* (F.J.P.)

The older person often thought that the hospital doctors were prescriptive, giving them no choice:

> *I had a spell in hospital and after that they said that I couldn't go home to my wife, I was too much trouble and too heavy, so I had to come here* [rest home]. (J.F.)

Another:

> *I had a big fight to get back here to my flat. The doctors and the others at the hospital wanted to put me in a rest home. They even had me booked into one. I had no relatives or anyone to speak for me, so I had to become really stroppy to get my way and come back here. I probably wasn't all that capable in hospital, but I knew that I would be better in my own environment. Once I got back here I began to improve and I can manage fine now.* (M.M.)

In other cases it was the family who wouldn't give the older person the choice:

> *I would like to go into a rest home, but my husband won't let me. I would get more attention there. He goes out too much and I never see him.* (B.A.)

From the NASC report:

> *The family decided that it was too dangerous for her to stay in her own house and they couldn't have her in theirs, so she was put in a rest home. It was the family's decision. Mrs K wanted to go back home.* (C.K. NASC)

Other people went into rest homes for respite care, and just continued on there after the respite had ended. In these cases it was usually the older person who found they enjoyed the residential care, or at least had more help, and felt more secure, so made the decision to stay in care. One man described his respite care experience as 'being treated like royalty'.

Most older people (90%) who were living at home felt they had a major influence on the decision about where they were going to live. Only a very small percentage (2%) felt they had no say in the decision to return home, as seen in Table 6.7. Just under half the people (46%) felt that their families had a major influence in the decision-making to return home. For those older people who entered residential care, their influence (54%) was much lower than those living at home (Table 6.8). However, the percentage of family having a major influence at home was similar to those in residential care (47%). A striking difference between those people in residential care and at home was in the influence of the hospital doctors. Few older people thought that the doctors influenced the decision to returning home (12%), while 40 percent of the older people felt that the hospital doctors had a major influence on the decision to enter residential care. The percentage of influence which the general practitioner had for those people living at home was doubled to 13 percent when the older people entered residential care. Interestingly, a similar percentage of older people and family (33%) were recorded as having no influence on the decision for the older person to live in residential care.

Table 6.7: Decision-makers for the older person to return home (N=123)

	Older person		Family		Hospital doctor		General practitioner	
Influence	**N**	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Strong	**111**	**90**	**56**	**46**	**15**	**12**	**9**	**7**
Some	**9**	**7**	**9**	**7**	**7**	**6**	**4**	**3**
Little	**3**	**2**	**58**	**47**	**101**	**82**	**110**	**90**

Table 6.8: Decision-makers for the older person to enter residential care (N=15)

	Older people		Family		Hospital doctor		General practitioner	
Influence	N	%	N	%	N	%	N	%
Strong	8	54	7	47	6	40	2	13
Some	2	13	3	20	0	0	2	13
Little	5	33	5	33	9	60	11	73

A Kendall's tau-b correlation of the three groups showed that the strongest relationship between the major influencer and residential care entry was the doctor. The strongest influencer to remain at home was the older person, although this was not significant. A chi-square confirmed these results. The Pearson's r correlation with the percentage of time to residential care entry showed that the doctor's influence decreased over time, while the older person's influence (and the family to a much lesser degree) increased over time (Table 6.9).

A regression analysis confirmed the previous results that the doctor was significantly involved in the residential care decision and three times more likely to be the decision-maker for residential care. The older person and family were more involved in the living at home decision, although the older person and family were not statistically significant (Table 6.10).

Table 6.9: Decision-makers correlated with residential care or home (N=131)

Decision-maker	**Kendall's tau-b**	**Chi-square**	**Pearson's r**
Doctors	0.209*	5.719**	-0.300**
Family	-0.071	0.666	0.003
Older person	-0.141	2.603	0.229**

P= significance, ** = p = < 0.01, * = p = < 0.05

Table 6.10: Odds ratio with significance and 95 percent confidence levels

Decision-maker	**B**	**S.E.**	**Wald**	**df**	**Odds ratio**	**Lower C.L.**	**Upper C.L.**	**p**
Doctors	1.083	0.499	4.712	1	2.953	1.111	7.850	0.030
Older person	-1.018	0.568	3.218	1	0.361	0.119	1.099	0.073
Family	-0.850	0.533	2.543	1	0.427	0.150	1.215	0.111

B = Unstandardised coefficients, S.E. = Standard error, Wald = Statistical significance of each coefficient

df = Degrees of freedom, C.L. = Confidence levels, p = Significance levels

It is interesting to note the variables associated with the doctor's decision-making, as shown in Table 6.11. There was a significant relationship between the doctor's decision-making and the older person's concern about falling, and their own ability to cope. The doctor's decision-making also had a significant association with both the knowledge of the support available within the community, and concerns about the support given within the community. The less the older person knew about community support, or the more concerned they were about the level or quality of support they were receiving (outside the family), the more involvement the doctors had with the decision-making.

To complete the picture of influence over decision-making, a correlation showed the older person's decision-making was significantly associated with their worry and concern that the family was doing too much, and with their efficacy or ability to control their own life. The family's decision-making was also significantly associated with the older person's efficacy, the older person's worry about the family doing too much, and not surprisingly with the family's own ability to provide support (Table 6.12). The next section examines how the older person felt about the decision.

Table 6.11: Other associations with the doctor's decision-making (N=131)

Variable	**Kendall's tau-b**
Knowledge of community support	-0.171*
Concern about falling	-0.255**
Concern about coping	-0.170*
Concern about community support	-0.177*

p = significance, ** = p < 0.01, * = p <0.05

Table 6.12: Other associations with the older person and family's decision-making (N=131)

Variable	**Older person**	**Family**
	Kendall's tau-b	Kendall's tau-b
Worry about the family doing too much	0.217**	-0.156*
Older person's efficacy	0.212*	-0.362**
Family support available	0.017	0.219**

p = significance, ** = p < 0.01, * = p <0.05

Residence

The residence theme describes where the older person was permanently living. The home was where one lived, or a fixed residence (Deverson, 1997). Therefore home could encompass the whole spectrum of living accommodations, such as family home, residential care, hospital, or the family's house. For this study, the term home referred to the living accommodation within the community. This included retirement villages and living with relatives, but excluded rest homes, continuing care hospitals and acute hospitals. Residential care was communal living, such as rest homes and continuing care hospitals. The major categories within this theme were home and residential care, as shown in Figure 6.9.

(i) Home. The term home conjured up many different pictures. Some older people said that home to them meant a garden, friends, sitting in peace having meals, independence, family, and family pets. At least 60 percent of the people had lived in their homes more than 10 years, with some remaining in their homes for over 50 years. There was a common reason for wanting to remain there and not wanting to relocate.

> *We have been here 50 years and I don't want to move. My wife finds it a bit hard, but I want to stay here.* (NK)

The first part of that quotation was heard many times throughout the study. People were living with concerns such as poor accessibility for ambulances, steps which could not be negotiated without two people assisting, and living on a hill. One man related how his wife had made their home 'age proof' with a water pressure lift from the back yard to the house. She also installed a night light, took out the bath, and installed a walk-in shower. Transport and accessibility to shops proved a problem, with poor taxi services and no close bus service. One man talked about his experiences with the taxi service:

> *I lost my licence and that has really put a dampener on my activities. The taxi service is really bad. It doesn't run on Sundays at all up here, we have to get a taxi from Lower Hutt all the way up here and they take an hour or so to get here. When we have called the taxi service and asked for one to be here at a specific time, the company only gives the driver eight minutes warning so if he is coming from Lower Hutt then he is going to be half an hour late. Sometimes they don't show up at all. I get frustrated.* (R.F.)

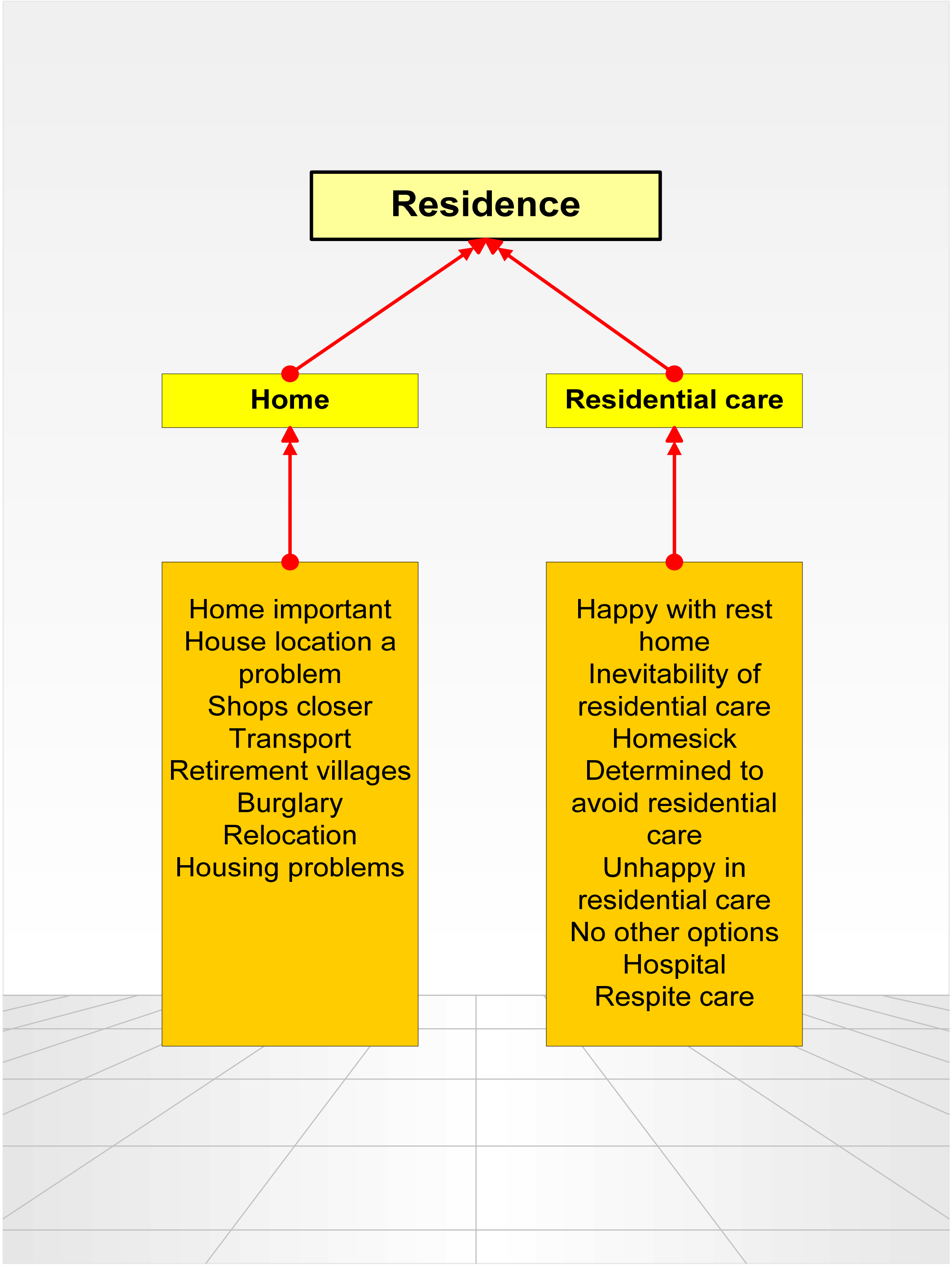


Figure 6.9: Codes and categories which make up the residence theme

Money concerns were raised by many of the older people as a barrier to moving into a retirement village, or getting a more suitable home. Many would have liked to be free from worries about money. One son persuaded his mother to sell her home, live with him and invest in his business. A year later he was declared bankrupt and the son's house was sold, which left the mother without a home. She is now renting a council flat and upset about the loss of her previous home. A few other older people had bought into their children's properties and said they were very happy living there and enjoyed having someone around.

Relocation was something that many older people did when they felt their family home had become too big, but primarily it was the garden that worried them most.

> *When my husband got sick, I couldn't look after the section by myself …we built a house that was small and easy to look after.* (PZ)

Another person said:

> *I moved to this house 20 years ago. My previous house was too big, well it wasn't the house really, although it did have four bedrooms and a sunroom, it was the garden.* (I.M.W)

Other more common reasons for relocating were to be nearer to family, or the house being unsuitable to live in because of steps. Retirement villages were a good option for some who felt that they were closer to services and 'like-minded people'. One person said the reason he wouldn't go in to a retirement village was because of the bad contracts they offered. Another said that she couldn't afford to buy into one, although she would like to.

(ii) Residential care. The three main areas included in residential care were acute hospital, respite care and rest home. Rest home was the broad term used in this study to include the people who needed high levels of support in the rest home. Also included in the rest home category were the people who needed very high levels of support and were in the continuing care hospitals. Respite care was usually a short stay within a rest home for a definite period, primarily for carer relief. Respite care could also be used as an interim from acute hospital to home, or in some cases to rest home. Acute hospital was either public or private, where the older person received active medical care for a specific illness or condition, for a relatively short period of time. Many older people who were admitted to rest homes had previously been in an acute hospital, and may also have been in respite care after discharge from hospital. The following report from the NASC was not uncommon:

> *The old lady had a fall and went into hospital. When it was time for discharge she went into respite care and from there just stayed in the rest home.* (M.R. NASC)

A few people went from home to respite care, and continued to stay in the facility providing the respite care, as in the case of C.W:

> *He went into respite and then just stayed there. The practice nurse referred him to residential care. He was very depressed at home and non-communicative, but now in the rest home he is very much happier and seems more alert too. Both the wife and the husband made the decision.* (C.W. NASC)

People perceived that there were only two options, staying at home with whatever support they were allowed, or going into a rest home. Many were resigned to going into a rest home when their health got worse. One lady in residential care said that she was sad in the rest home, but there was no other option. Another older person said he would love to go home, but he guessed that he couldn't manage anywhere else. The following was one person who was resigned to going into the rest home:

> *I feel that my health is getting worse and soon I will have to go into a rest home, and I did not want that, although I know that they are much nicer now and alright, but still it is a bit of a shift. But if I can't manage and they are telling me I can't, then I guess that is the best place for me really.* (M.J.P.)

Another lady thought that going into a rest home comes to everyone if you live long enough:

> *Oh yes that* [going into the rest home] *was the wisest thing to do really wasn't it. It is not my cup of tea this sort of life, but I mean it comes, well if you live long enough it comes to us all possibly.* (M.G.)

A few people were adamant that they would remain at home, and be 'carried out in a box' like their spouse.

6.4: The older person's feeling about the decision

Feeling described the amount of happiness or sadness the older person felt with the decision about where they lived. This section examined the results and compared the initial and six-month interviews, to test the timing of the question and if the feeling over the decision changed over time. With few people living in residential care at the initial interview, the feeling about the decision at that time was mainly about remaining at home. The feelings of the older person were rated from 1, very sad, to 5, very happy. Because of the small numbers in some categories 1 to 3 were grouped together and so were 4 to 5. Table 6.13 demonstrated that in all three tests (Kendall's tau-b correlation, chi-square and Pearson's r correlation), there was a statistically significant association between the older person's feeling and where they lived, at both interviews.

Table 6.13: Older person's happiness with decision over six months

N	Interview	Kendall's tau-b	Chi-square	Pearson's r
131	Initial	-0.25**	8.156**	0.387**
92	Six month	-0.353**	11.226***	0.319**

p = significance, ** = p < 0.01, *** = p = < 0.001

A further test, the Mann-Whitney U test showed a significant difference between the feeling of the older person at home and residential care, as seen in Table 6.14.

The feelings of the people who at any time entered residential care and those at home were compared with the feelings of the same groups of people after six months. At the first interview, as stated previously, most of the people were at home, but it was of interest to see if their happiness with the decision changed when they went into

Table 6.14: Older person's happiness with decision at home and residential care

N	Interview	Residence	Mean rank	Sum of ranks	Mann-Whitney U	p (2 tailed)
103	Initial	Home	68.97	7310.5	1010.5	0.004
28[a]		Residential care	53.42	1335.5		
73	Six month	Home	49.17	3589.5	352.5	0.001
19		Residential care	29.74	505.5		

p = significance, a = people who entered residential care at some time throughout the study.

residential care. That was the reason for grouping all the people who had entered residential care at any time within the first interview, as shown in Table 6.15.

There was evidence of the considerable difference in the way the older person felt about the decision regarding where they were living, between the initial interview (when most people were at home) and the interview six months later, as shown in Table 6.15 and Figure 6.10. It is evident that the happiness about the decision of location at both home and residential care decreased over time, but this is most evident with residential care. The number of people stating that they were happy in residential care decreased from the initial interview to the six-month interview. The same was true for those people living at home, although to a much lesser degree.

The relationships between the older person's feelings were tested to see if other variables significantly interacted with them. Their feeling was significantly associated with their concern about their health at the initial interview ($\tau = 0.178$, $p = 0.05$), and their efficacy at the six-month interview ($\tau = 0.213$, $p = 0.05$). This means that at the initial interview when they were least concerned about their health, they were most happy with the decision about where they lived. The relationship with their efficacy showed that if they were feeling that they had control of their day-to-day decisions, they were also most happy with the decision of where they lived.

Table 6.15: Comparison between the two interviews: happy and sad, and home and residential care

N		Residence	Older person happy	%	Older person sad	%
103	Initial interview	Home	93	88	13	12
28[a]	Initial interview	Residential care	16	64	9	36
131	Total		109	83	22	17
73	6 month Interview	Home	53	73	20	27
19	6 month Interview	Residential care	5	29	12	71
92	Total		58	64	32	36

a = people who entered residential care at some time throughout the study.

One older person said she really enjoyed living at the rest home with the friendly atmosphere, and the fact there were lots of people to talk to. Others were sad, particularly if they had left a spouse at home. The change of environment and habits was hard for some, as indicated below:

> *Yes I miss that, [home] yes you do really, you can more or less have what you want at home, it is not the same at all really. But they are very good here [rest home] and you certainly don't go hungry, but it*

> *is not quite the same. It is a bit of a loss. I do go to bed quite early here because there is nothing else to do here. I get up at 7am to have a shower, it is very early. I never did that at home.* (M.F.)

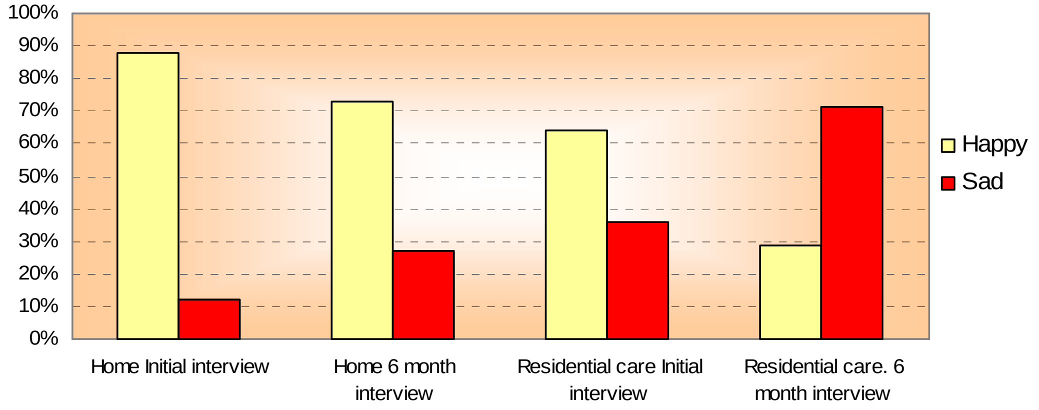


Figure 6.10: The older person's happiness over the six-month period.

6.5: Older people's wish for change

As a way of gaining insight into the older person's satisfaction with the residence decision, the older people in the study were asked "if you could change one thing what would it be?". Table 6.16 illustrates the six major themes that were developed from the 29 changes mentioned by the older people. Two themes took up 61 percent (n= 79) of the changes, and two took up 28 percent (n= 36). The changes were grouped into themes which were descriptively designated by the nature of the changes, or in some cases, no changes. These were listed in order of popularity: health, no change, self, family, house, and services. To define the changes further, Tables 6.17, and 6.18 examined the differences in the age groups and genders.

Health

Results indicated that the majority of older people (33%) expressed a wish for health changes, such as being free of their arthritis, being more mobile, or wished they had not started smoking. The youngest group of 66 to 79-year-old people mentioned health more frequently at 42 percent, (Table 6.17), while the other two groups were at 28 and 30 percent. Health-related change (Table 6.18) was the preferred change for most females. However, when an adjustment was made to correct for the different numbers of males and females in the study, there was a larger percentage of the male group at 37 percent choosing health than that of the female group at 31 percent.

No Change

The no change theme which included the ‘don’t knows’, was the second most often mentioned (28%). It was the theme often chosen by people over the age of 90 years (37%). It was also the highest preference of the 80 to 89 age group at 30 percent. It appeared that over twice as many females wanted no change, but when this was adjusted to the group numbers it was closer at 30 percent to 24 percent. The youngest group were much more interested in change, and particularly the health change, than the option of no change.

Self

This was the most diverse theme, and included personal changes such as wanting more money, to living life over again differently, or to being younger. Of the total themes, this was ranked third (15%), but was much less often mentioned than the previous two. When number adjustments for the groups had been made, there was no significant difference between any of the groups in this theme, with a range of 17 percent to 13 percent, although males at 20 percent were almost twice as interested in self as females at 12 percent.

Family

This theme most often included a wish to have a spouse back, or more family contact. Females choosing the family change far outstripped the males in the total numbers and in the adjusted figures (17% to 7%). Family ranked third above the self theme for females, and well below self for males at 20 percent to 7 percent. The age group which most often mentioned family was the 80 to 89-year-old people in both unadjusted and adjusted figures (19%) with the youngest group mentioning it least (7%).

Table 6.16: Major themes and categories for the wished for changes (N=129)

Major themes	**%**	**Changes suggested by the older person**	**n**
Health	33	To be more healthy	23
		To be more mobile	17
		To never have started smoking	2
		Not to be incontinent	1
No change	28	No change	31
		Don't know	4
		To have peace in the world	1
Self	15	To have done more things when younger	1
		To have more money	6
		To be younger	6
		To live my life over again differently	1
		Not to be a bother to anyone	2
		To drive my car again	1
		For my cat to come home	1
		To go to Australia	1
Family	13	To have spouse back or healthy	11
		To have more family contact	3
		To get married again	1
		To have a family	1
		For my son to communicate with me	1
House	6	To change house	5
		To have the shops closer	2
		To stay in my own home	1
Services	5	Combine the services given to me	1
		To improve the way they organise this hospital	1
			1
		To have more help	1
		Better talking books	1
		To get a scooter	1
		To have more interesting visitors	1

Housing and services.

These themes at 6 and 5 percent were the least popular, and included a variety of changes, with a change of house the most often mentioned. These themes had relatively small numbers with similarities in all groups, as well as genders. It was interesting to note that in the 66 to 79 age group housing ranked above family at 11 percent. More males chose this change, while no one in the 90-plus age group made housing their first choice for change.

Of the 29 changes, 12 were repeated more than once. The most popular was no change, where people thought that they couldn't, or wouldn't want to change anything now, or simply didn't know what they would change. To be more healthy (n=23) included changes to the older people's existing medical conditions, such as to be rid of arthritis, to be free of the need for the respirator, or to be free of the pain in their back. To be more mobile (n=17) encompassed those who wished they could discard their wheelchairs, walking frames, to be able to do a little gardening, or housework. Mostly the change to have a spouse back (n=11) was a widow or widower, but a few were included in this theme who wanted their spouses to be more healthy. The other changes included wanting to be younger, wanting more money, and a variety of other less often mentioned changes.

The changes mentioned by the 16 people who were classified as needing very high levels of support followed along the general trend of most mentioning the health theme (n= 7) followed by the no change theme (n= 6). Interestingly, of the people who did not have a designated carer, more opted for no change, while those with designated carers wished more often for more family involvement. The differences between age and gender groups were tested using chi-square, which showed no significant difference.

The themes from the 'wished for changes' (health, self, family, house, services) replicated themselves throughout the whole study. The themes of the qualitative findings were built up to form the model in Figure 6.11.

Table 6.17: Age group differences between the changes

Ages **Themes**	**66-79** n	**80-89** n	**90-101** n
Health	19	15	9
No change	9	16	11
Self	6	9	4
Family	3	10	4
Housing	5	3	0
Services	3	1	2

Table 6.18 Gender differences between the changes

Gender **Themes**	**Males** n	**Females** n
Health	17	26
No change	11	25
Self	9	10
Family	3	14
Housing	4	4
Services	2	4

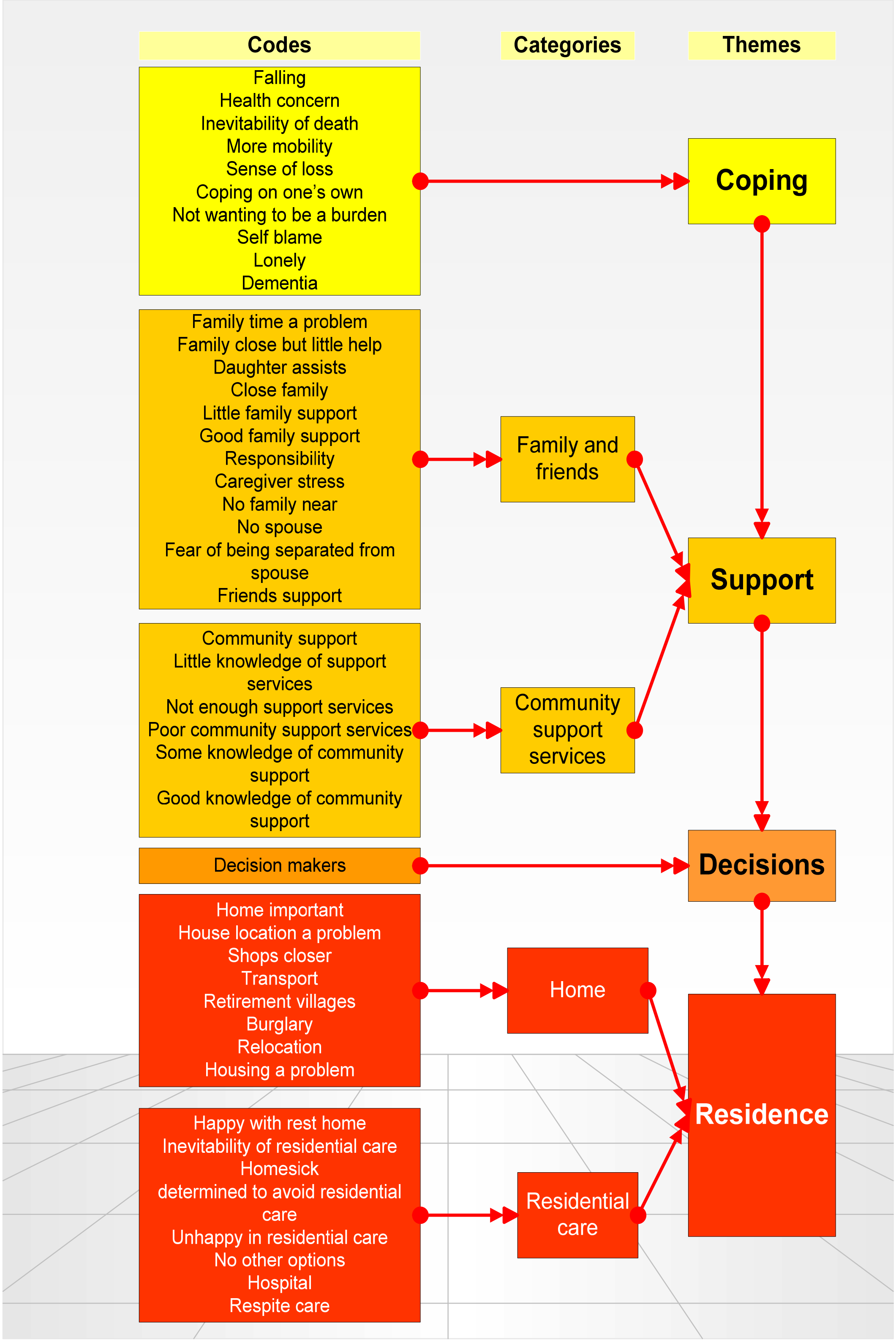


Figure 6.11: Themes, categories and codes for Model 3

6.6: Summary of Part 1: Findings

The qualitative findings commenced with a literature review (Model 1), which identified areas of risk of entering residential care, and the people who made the residence decisions. Several major risk factors for residential care entry were highlighted, such as, being over 80 years of age, living alone, carer not coping, being of European descent, difficulty with daily functions, and cognitive dysfunction. The model progressed through a pilot study (Model 2), which identified three major themes; changes, which demonstrated the need for change within the older person's environment, while the control theme showed who had the control of the decision making process. Placement illustrated where the older person was to reside and how happy they felt about that decision.

A sequential model was developed from the themes for Model 3 which were: coping, support, decisions and residence. These themes described the stages and processes which the older person (and, where possible, their carer) went through, as well as thoughts from the NASC. It was clearly shown that while the doctor had the most influence over the person's going into residential care, the older person had the most influence about staying in their own homes. The residence theme described the older person's satisfaction with the residence decision. The vast majority of older people felt that they had a major influence in their residence decision, with the family being the next most popular decision-maker. At the first interview when most were living at home, there were more people happy than sad, but unfortunately this changed dramatically at six months, particularly for the people in residential care, where the great majority of the people were unhappy.

The most commonly wished for change was a change in health status, followed closely by a satisfaction with the status quo. Overall the older people were happier at home, were most concerned about their health issues, and felt that they had significant input into the decision of whether they would continue living at home or move to residential care.

Part 2: Risk factors

Proof is an idol before which the mathematician tortures himself

Sir Arthur Eddington (1882-1944)

While Part 1 reported the qualitative data which covered the interpretation of the relationships between variables, Part 2 reports the actual relationships between the variables (Punch, 2005). It progresses from the broad screening of the variables for their significance with the older person's place of residence, either residential care or home, to specific relationships which by their reaction or relationship with each other, might influence residential care entry. Two sets of data are discussed OPERA (N = 131) and ASPIRE (N=569). In order to have similar data bases when the two databases were joined in the final step (Step 3) only the participants in ASPIRE who also were in OPERA (N=131) were used. The term variable is used throughout Part 2 to signify a factor which might influence the decision-maker to take the residential care option.

The variables in both OPERA and ASPIRE were screened for significant relationships with the older person living in residential care, or living at home, by: (i) Kendall's tau-b (τ) and Chi-square (χ^2) was used to check the associations to allow for the possibility of skewed distributions. The same level of association was evident in all areas. (ii) Pearson's correlation (r) used the percentage of time from the support needs assessment (and study entry) to residential care entry as its dependent variable, to also screen for significant relationships with the variables. The Pearson's r correlation was used as a check for the validity of the Kendall's tau-b correlation (Appendix Table A.6.1 and Table A.6.2). The older people in OPERA (Table 6.19) who were in residential care at the initial interview discussed their concerns retrospectively; hence their comments are related to their home situation rather than the residential care. Interestingly, no concern was statistically significant at both the initial and six-month interviews. This could lead to the assumption that the significant concerns at the initial interview showed more active participation in the older person's wellbeing, than six months later when some of the older people were in residential care.

The questions from OPERA in Table 6.19 were all structured around what concerns would be important enough to make the older person consider residential care entry. A correlation process (Kendall's tau-b) was used to determine those variables which were significantly related to either the older person being at home, or living in residential care. All the statistically significant concerns except for self-efficacy were significantly related to living at home. The scales for the OPERA variables were ranked from the low scores (1) being of greatest concern to the higher (5) of least concern. The highest significant correlation for the older person living at home was about their housing ($\tau = -0.442$, $p = <0.001$). This showed a concern for areas, such as, access to the bathroom, hard to negotiate steps, or difficult access from the road. Other significant correlations relating to home were about the community support ($\tau = -0.273$, $p = <0.001$) at the initial interview, and at the six-month interview, the knowledge of what support was available ($\tau = -0.394$, $p = <0.001$). The concerns about the community support included the caregiver not showing up for work, the caregiver's inability to perform the tasks required of them and also the knowledge of what help was available to the older person.

Concern about family support ($\tau = -0.282$, $p = <0.001$) and the worry that the family were doing too much ($\tau = -0.182$, $p = <0.005$) were both significant at the initial interview. When family were assisting, the older person would often worry that they were spending too much of their time helping them. Some older people also felt that they were being too much of a bother to the family. At times the older person would have concerns over the way the family support was given, or the pressure from the family to move away from home, or their way of living.

The statistically significant correlations with home and coping ($\tau = -0.237$, $p = <0.001$) at the initial interview, and residential care and self-efficacy ($\tau = 0.383$, p

$= <0.001$) at the six-month interview, were about the older person’s ability to manage on a day-to-day basis. It could be assumed that as the older person’s condition progressed and residential care became more of an option, their feeling of self-efficacy would be of some concern to them. This is shown by self-efficacy being significant at the six-month interview. A similar assumption of the older person’s worsening condition could be made for the older person's coping skills. Health, not surprisingly, was statistically significant with the home, at the initial interview only ($\tau = -0.265$, $p = <0.001$). It is assumed that as the person’s condition deteriorated, more support services were put in place, or that the residential care option would be taken, therefore taking the concern away from health.

The variables significantly correlated to residential care status from ASPIRE differed between interviews (Table 6.20). Unlike the OPERA questionnaire the scoring for the ASPIRE scales were structured to show a higher score meaning a greater degree of disability. The three variables which were statistically significant at all interviews were: a dependence with the higher functioning activities of daily living (IADL), a dependence with the activities of daily living (ADL), and cognitive performance (CPS). These three variables progressed in significance from the initial interview to the fourth interview (T_3) and then the significance lowered for the fifth (T_4) possibly due to the greatly reduced numbers of participants at this interview. The significance of the IADL scale rose from the initial interview $\tau = 0.164$, $p = <0.001$ to $\tau = 0.401$, $p = <0.001$ at the forth interview and similarly for the ADL $\tau = 0.146$, $p = <0.001$ to $\tau = 0.340$, $p = <0.001$and cognitive performance scales $\tau = 0.175$, $p = <0.001$ to $\tau = 0.363$, $p = <0.001$. These three variables were related to moving into residential care.

Table 6.19: Older people's concerns correlated with residential care status # (N=131)

	OPERA Variables	**T_0 Kendall's tau-b**	**T_0 Chi-square**	**T_1 Kendall's tau-b**	**T_1 Chi-square**
Statistically significant	Concern about housing	-0.442**	37.036***	-0.041	0.142
	Concern about family support	-0.282**	10.400***	0.067	0.386
	Concern about community support	-0.273**	9.779**	-0.167	5.674
	Concern about health	-0.268**	10.684**	0.906	1.265
	Concern about coping	-0.237**	11.763**	-0.014	0.173
	Concern family doing too much	-0.182*	13.337	-0.023	1.462
	Knowledge of community support	-0.056	6.005	-0.394**	14.929**
	Efficacy	-0.025	0.081	0.383*	5.877**
Not statistically significant	Concern about falling	-0.141	4.863	0.054	1.575
	Concern about shopping	-0.128	2.799	nil	nil
	Family support available	-0.090	1.806	0.153	4.517
	Concern about burglary	-0.086	1.649	nil	nil
	Concern about being lonely	-0.081	0.960	0.131	1.452
	Concern about money	0.002	0.002	0.240	2.298

p = significance, *** = p= 0.001, ** = p = 0.01, * = p = 0.05, T = interview, 0 = initial, 1 = 6 month
# Note: 1 = living at home, 2 = living in residential care. A positive correlation indicates that the concern was associated with residential care.

Table 6.20: Variables predicting shift into residential care (N=569)

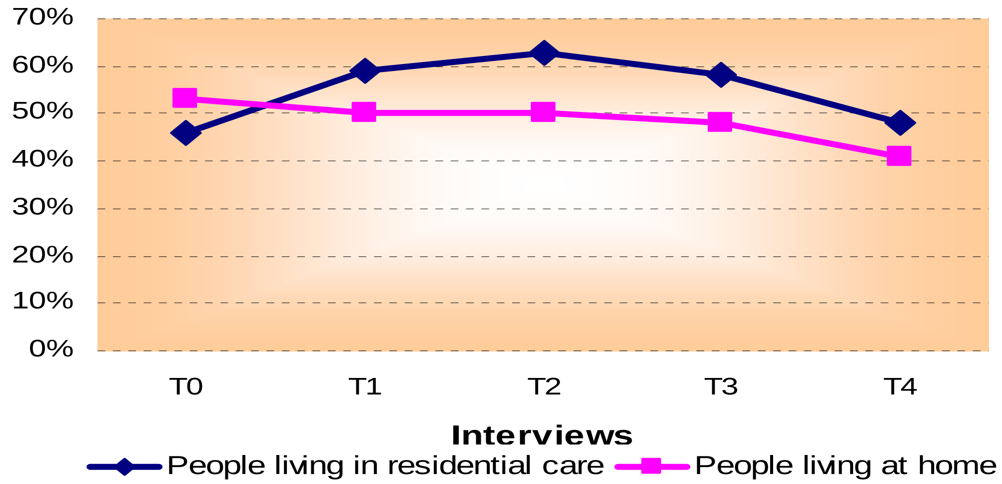
	ASPIRE	**T_0**	**T_1**	**T_2**	**T_3**	**T_4**
	Variables	**Kendall's**	**Kendall's**	**Kendall's**	**Kendall's**	**Kendall's**
Statistically significant	IADL	0.164**	0.317**	0.345**	0.401**	0.360**
	ADL	0.146**	0.373**	0.306**	0.340**	0.296**
	CPS	0.175**	0.256**	0.250**	0.363**	0.313**
	Not seeing friend	0.068	0.060	0.125**	0.126**	0.210**
	Not seeing neighbours	0.014	-0.019	-0.056	-0.123**	-0.296**
	Not being home alone	-0.016	-0.137**	nil	-0.338**	-0.400**
	Sibling far away	0.064	0.109**	0.085*	0.125**	0.048
	Child far away	-0.003	0.127**	0.050	0.110	0.134
	CHESS	0.075	0.150**	nil	0.149**	0.127
	Pain scale	-0.028	-0.006	-0.143**	-0.109	-0.041
	Not seeing family	-0.052	-0.070	-0.020	0.101*	0.037
	Family far away	0.197*	0.120*	nil	0.097*	0.064
Not statistically significant	Depression scale	0.066	0.064	0.094	-0.048	0.081
	Caregiver stress	0.089	0.034	0.030	-0.131	-0.104
	Prior hospital admission	-0.070	0.043	0.087	0.061	0.029
	Lonely	0.024	0.079	nil	-0.009	0.024

CHESS = Changes in health, end-stage disease and signs and symptoms, p = significance, ** = p <0.01, * = p <0.05

T = interview, 0 = initial, 1 = 3 month, 2 = 6 month, 3 = 12 months, 4 = 18 month, nil = data incomplete for that interview, Kendall's = Kendall's tau-b, IADL = Instrumental activities of daily living, ADL = Activities of daily living, CPS = Cognitive performance scale. Note: For the variable 'residential care or home', 1 = living at home, 2 = living in residential care. A positive correlation indicates that the concern was associated with residential care.

Two other significant variables related to the older person's support at home: not seeing their neighbour, and the older person not being alone for long periods at home. These were significant at the 12-month (T_3) ($\tau = -0.123$, $p = <0.001$ and $\tau = -0.338$, $p = <0.001$ respectively), and 18-month interviews (T_4), ($\tau = -0.296$, $p = <0.001$ and $\tau = -0.400$, $p = <0.001$ respectively). Not being home alone was also significant at the three-month interview ($\tau = -0.137$, $p = <0.001$). Both were related to living at home. Not seeing a friend, family living far away, and a sibling living far away were significant variables at three of the interviews.

Several studies have found that prior hospitalisation was a very important predictor of residential care entry (Bebbington et al., 2001; Miller & Weissert, 2000). Figure 6.12 could possibly support this finding, but rather than showing a great diversity, showed only a minimal difference between the two groups. The percentage of people at each interview (within ASPIRE, N=569) with prior hospital admissions was slightly greater for the residential care group at all but the initial interview. However, older people living at home and residential care, regardless of prior hospital admissions, spoke of the doctors' residential care preference. From the verbal reports there did appear to be a trend from hospital to respite care to residential care. From the statistical point of view, there was no significant relationship with prior hospital admissions and the variable 'residential care or home'. For the variable which contained the percentage of time from assessment to residential care entry, the results were more mixed, with the overall scores showing a significant relationship only at the six-month interview ($r = -0.97$, $p = 0.05$). This result, being negative, showed a relationship with home. When only those people in residential care were tested, there was a positive relationship with prior hospital admissions at the eighteen-month interview only ($r = 0.399$, $p = 0.05$). This would appear to indicate that the longer the person waited after the support needs assessment, the more likely it was that going into hospital would also lead to residential care entry.



T= Interview, 0= initial, 1= 3 month, 2= 6 month, 3= 12 month, 4= 18 month

Figure 6.12: People at each interview who had prior hospital admissions

The factors which correlated significantly with residential care entry are shown in Table 6.21. The OPERA interviews were initially and six months later, while the ASPIRE interviews were initially, three months, six months, one year and eighteen months. The ASPIRE interviews at one year and eighteen months were approximately at the same time as the two OPERA interviews. The most significant correlations were the IADL, ADL and cognitive performance scales. These were scored from 0 (no dependence for these functions or no cognitive loss) to severely impaired: 21 and 6 for the IADL and ADL respectively, and to 6 for the CPS scale. More dependence on others for the daily living skills (IADL and ADL), or a high cognitive loss (CPS), correlated with the move into residential care. The most significant correlations which would indicate staying at home were concerns about housing and the family support.

While it was evident that while any one of the significant variables shown in the correlation could have hastened residential care entry, there could also have been variables which worked together, or against each other, to encourage the move. Three progressive stages using binary logistics regression were developed to demonstrate how the variables interacted in groups. This process helped isolate

Table 6.21: Significant relationships with shift to residential care

	T_0	T_1	T_2	T_3	T_4
Variables	**Kendall's tau-b**	**Kendall's tau-b**	**Kendall's tau-b**	**Kendall's tau-b**	**Kendall's tau-b**
ASPIRE (N=)					
Instrumental activities of daily living scale	0.164**	0.317**	0.345**	0.401**	0.360**
Activities of daily living scale	0.146**	0.373**	0.306**	0.340**	0.296**
Cognitive performance scale	0.175**	0.256**	0.250**	0.363**	0.313**
Not seeing friend			0.125**	0.126**	0.210**
Not seeing neighbour				-0.123**	-0.296**
Not being home alone		-0.137**		-0.338**	-0.400**
Sibling far away		0.109**	0.085**	0.125**	
Child far away		0.127**			
CHESS		0.150**		0.149**	
Pain scale			-0.143**		
Family far away	0.197*	0.120*		0.097*	
OPERA (N=131)					
Concern about housing	-0.442**				
Concern about family support	-0.282**				
Concern about community support	-0.273**				
Concern about health	-0.268**				
Concern about coping	-0.237**				
Concern family doing too much	-0.182**				
Knowledge of community support		-0.394**			
Efficacy		0.383*			

CHESS = Changes in health, end-stage disease and signs and symptoms, p = significance, ** = p <0.01, * = p <0.05

T = interview, 0 = initial, 1 = 3 month, 2 = 6 month, 3 = 12 month, 4 = 18 month. For the IADL, ADL, CPS, CHESS and Pain scales the higher scores indicates greater dependence or disability. For the variable 'residential care or home', 1 = living at home, 2 = living in residential care. A positive correlation indicates that the concern was associated with residential care.

the variables which were most important in influencing residential care entry. The 12-month interview (T_3) from ASPIRE and initial interview (T_0) from OPERA were taken for the building of the stages. These interviews were selected because they were at a similar time, and there were many more ASPIRE participants at the 12-month interview than at the 18-month interview.

Stage 1 grouped and examined all the variables which had a significant correlation with the variable residential care or home from both ASPIRE and OPERA (Table 6.22). Within this model four variables from the ASPIRE group proved to be of statistical significant. Two were showing a significant risk of residential care entry, which were: the older person's increased dependence for activities of daily living tasks (IADL), and having not having a child living in close proximity to the older person. The other two variables showed that the older person is more likely to stay at home. Those were: the older person not being home alone for long periods, and not seeing their neighbour very often. The results from the cognitive performance scale and having the family living far away were not statistically significant within this group. Out of OPERA, both statistically significant variables were related to staying at home; which were: concern about housing, and concern about family care.

The four significant variables from ASPIRE and the two from OPERA were taken to form new groups of variables in Stage 2 which would identify how they interacted together, with the variable residential care or home. All variables remained statistically significant, with only minimal downward changes in the odds ratios in Stage 2 (Table 6.23). Within Stage 2, with this group of ASPIRE variables, there was 30 percent increased risk of the older person entering residential care for every step of the IADL scale showing increasing dependence (0 means the person is independent, to 21 where the person is highly dependent). Having a child living far away also increased the risk of residential care entry for the older person by 30 percent for every step of the scale (0 means the person is living with their child, to 5 where the child is over 80 kilometres away). The two areas which decreased the risk of residential care entry were the older

Table 6.22: Stage 1. Odds ratio for significant variables predicting residential care (95 percent confidence levels)

Stage 1 Variables	B	S.E.	Wald	df	Odds ratio	Lower C.L.	Upper C.L.	p
ASPIRE (N=569)								
IADL	0.329	0.060	30.447	1	1.389	1.236	1.562	<0.0001
Child far away	0.261	0.132	3.889	1	1.298	1.002	1.682	0.049
Not seeing neighbour	-0.335	0.099	11.537	1	0.715	0.590	0.868	0.001
Not being home alone	-0.649	0.215	9.144	1	0.523	0.343	0.796	0.002
CPS	-0.229	0.140	2.671	1	0.796	0.605	1.047	0.102
Sibling far away	0.104	0.119	0.776	1	1.110	0.880	1.401	0.378
Not seeing friend	0.095	0.130	0.529	1	1.099	0.852	1.418	0.467
Pain	-0.127	0.177	0.510	1	0.881	0.622	1.247	0.475
CHESS	0.058	0.183	0.100	1	1.060	0.740	1.518	0.752
Family far away	0.058	0.330	0.031	1	1.060	0.555	2.023	0.860
OPERA (N=131) Concerns:								
Housing	-1.572	0.462	11.587	1	0.208	0.084	0.513	0.001
Family care	-2.435	1.077	5.110	1	0.088	0.011	0.723	0.024
Community support	-1.105	0.581	3.613	1	0.331	0.106	1.035	0.057
Family doing too much	-0.454	0.266	2.919	1	0.635	0.377	1.069	0.088
Health	-0.441	0.387	1.297	1	0.643	0.301	1.375	0.255
Coping	-0.262	0.238	1.212	1	0.769	0.482	1.227	0.271
Knowledge of support	-0.232	0.340	0.465	1	0.793	0.407	1.545	0.495
Self-efficacy	0.377	0.658	0.328	1	0.686	0.189	2.491	0.567

B = Unstandardised coefficients, SE = Standard error, Wald = Statistical significance of each coefficient, df = Degrees of freedom, CL = Confidence levels, p = Significance, IADL = Instrumental activities of daily living, CPS = Cognitive performance scale, CHESS = Changes in health, end-stage disease and signs and symptoms.

person not being home alone for long periods and, interestingly, not seeing a neighbour. From OPERA, not being concerned about housing and also not having concerns about the family's provision of care decreased the risk of residential care.

Table 6.23: Stage 2. Odds ratio for variables predicting residential care significant in Stage 1

Stage 2 Variables	B	S.E.	Wald	df	Odds ratio	Lower C.L.	Upper C.L.	p
ASPIRE (N=569)								
IADL	0.300	0.048	38.554	1	1.350	1.228	1.484	<0.0001
Child far away	0.268	0.128	4.357	1	1.307	1.016	1.682	0.037
Not seeing neighbours	-0.332	0.091	13.445	1	0.717	0.601	0.857	<0.0001
Not being home alone	-0.620	0.210	8.694	1	0.538	0.356	0.812	0.003
OPERA (N=131) Concerns:								
Housing	-1.767	0.408	18.786	1	0.171	0.077	0.380	<0.0001
Family care	-2.441	0.817	8.927	1	0.087	0.018	0.432	0.003

B = Unstandardised coefficients, SE = Standard error, Wald = Statistical significance of each coefficient, df = Degrees of freedom, CL = Confidence levels, p = Significance, IADL = Instrumental activities of daily living scale.

Stage 3 is the combination of both the OPERA and ASPIRE (N=131) significant variables (Table 6.24). This stage was developed to test all the variables working together to see how they interacted. However, in order to join the groups only those participants from ASPIRE who were also in OPERA could be included in this model, which as a result reduced the number of ASPIRE participants to 131. For the tables to be compatible the scores (in this model only) for the concerns about housing and family care were reversed. When the two groups were joined, only one variable; increased dependence (IADL) remained significant. Within this group an increased dependence led to the older person being approximately three times at risk of residential care entry for every step up the scale, from 0 being completely independent, to 21 totally dependent. Stage 3 is only a small segment of the ASPIRE group, so it is helpful to examine both Stage 2 (which has the 569 people from ASPIRE) for the detail of the various risks and Stage 3 when looking at the one overall significant risk factor.

Since people who were highly dependent, as shown by the IADL scale, proved highly significant in their relationship with residential care entry, other linear relationships were tested. The older people were divided into two groups, low dependence and high dependence (by the scree test described in Chapter 3, Methods), and the linear relationship was tested by the Kendall's tau-b test. The test showed there was a linear relationship between cognitive skills and high dependence on the IADL scale. Therefore, as people became more dependent, they would also be highly likely to be more cognitively impaired. There was a non-linear relationship with the other variables tested (Table 6.25).

Only two people out of the sample tested with low dependence scores (IADL at or below 10 on a scale of 0 to 21) were in residential care at the 12-month interview (193 were living at home). Therefore it was of interest to compare the people with high dependence scores who were living in residential care and living at home. Cognitive performance, as expected, was higher in people living in residential care, which was similar for people who had lived alone and whose family lived far away. There were more people at home who expressed being lonely, and more people at home who were not home alone for long periods. It is perhaps understandable that people at home were more concerned about their housing, their coping abilities, health and community support, yet it seems that the worry about the family doing too much does not decrease when the person enters residential care (Table 6.26).

Increasing age was not shown to be significant when associated with either living in residential care or living at home. However, age was shown to be significantly associated with residential care entry when correlated with the percentage of time from assessment to residential care entry ($r = 0.114$, $p = 0.01$). This would mean that the longer the older person waited after the assessment, the more likely they would be to enter residential care.

Table 6.24: Stage 3. Odds ratio for variables predicting residential care significant in Stage 2

Stage 3 Variables N=131	B	S.E.	Wald	df	Odds ratio	Lower C.L.	Upper C.L.	p
ASPIRE and OPERA								
IADL	0.868	0.329	6.983	1	2.383	1.251	4.538	0.008
Concerns about housing (R)	-1.861	1.061	3.079	1	0.155	0.019	1.243	0.079
Concerns about family care (R)	-4.036	2.351	2.947	1	0.018	0.000	1.771	0.086
Child far away	0.763	0.532	2.055	1	2.144	0.756	6.082	0.152
Not being home alone	0.887	0.992	0.799	1	2.427	0.347	16.962	0.372
Not seeing neighbour	-0.212	0.355	0.357	1	0.809	0.404	1.621	0.550

B = Unstandardised coefficients, SE = Standard error, Wald = Statistical significance of each coefficient, df = Degrees of freedom, CL = Confidence levels, p = Significance, IADL = Instrumental activities of daily living scale, (R) reversed scoring of OPERA to match ASPIRE.

Table 6.25: Relationships between people with high and low IADL scores

IADL	**Dependence high >10**	**Dependence low ≤10**
Key Variables	**Kendall's tau-b**	**Kendall's tau-b**
CPS	0.395**	0.227**
Depression	0.159**	0.014
Family far away	0.175**	0.023
Not being home alone	-0.375**	0.033

IADL = Instrumental activities of daily living scale, p = significance, ** = p<0.01, high dependence >10 on a scale of 0-21.

CPS = Cognitive performance scale.

Table 6.26: Comparison of the mean scores of people with high dependence (IADL) in residential care and at home

Variable	Residential care Mean	Home Mean	Scale
Cognitive performance scale	2.44	1.34	0- intact to 6- severe impairment
Lonely	0.21	0.25	0- no to 1- yes
Not being home alone	0.34	1.04	0- never to 3- always
Living alone	0.53	0.27	0- no to 1- yes
Family far away	1.38	1.23	0- within a mile to 5- 50+ miles
Child far away	2.69	2.09	0- under 1 mile to 5- 50 + miles
Concern about family doing too much	2.79	2.80	1- often worry to 5- never worry
Concern about housing	2.47	3.82	1- very concerned to 4- unconcerned
Concern about coping	2.00	2.55	1- very concerned to 4- unconcerned
Concern about health	3.29	4.00	1- very concerned to 4- unconcerned
Concern about community support	3.47	4.00	1- very concerned to 4- unconcerned

High dependence = Instrumental activities of daily living scale scores >10

Caregiver stress did not show a positive correlation with either living in residential care or living at home, but it did correlate significantly with the percentage of time taken from assessment to residential care entry ($r = 0.192$, $p= 0.05$). This showed that the longer the caregiver had to look after the older person after assessment, the more likely they were to enter residential care. More striking perhaps was the strong association between caregiver stress and the older person's pain ($\tau = 0.185$, $p = 0.01$; $r = 0.241$. $p = 0.01$). The more pain the older person had, the more likely that the caregiver's stress increased. The stress and pain were also affected by time; the longer the time the older person had the pain, the more stress there was for the caregiver. Understandably, the older person's worry about the family doing too much was positively correlated with caregiver stress (τ = 0.282, p = 0.05). Figure 6.13 illustrates the caregiver's stress at the different interviews and how the stress increased slightly as the time at home after the needs assessment progressed, and decreased slightly when the older person entered residential care.

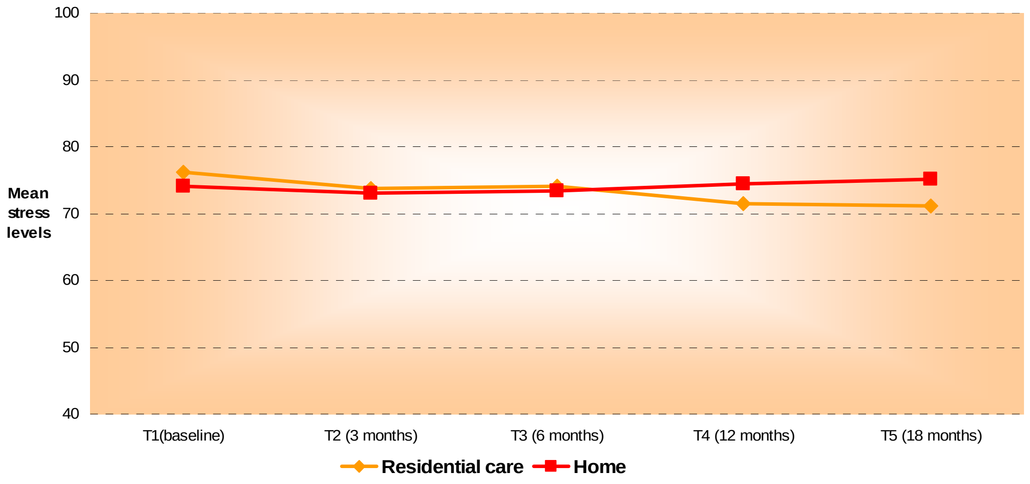


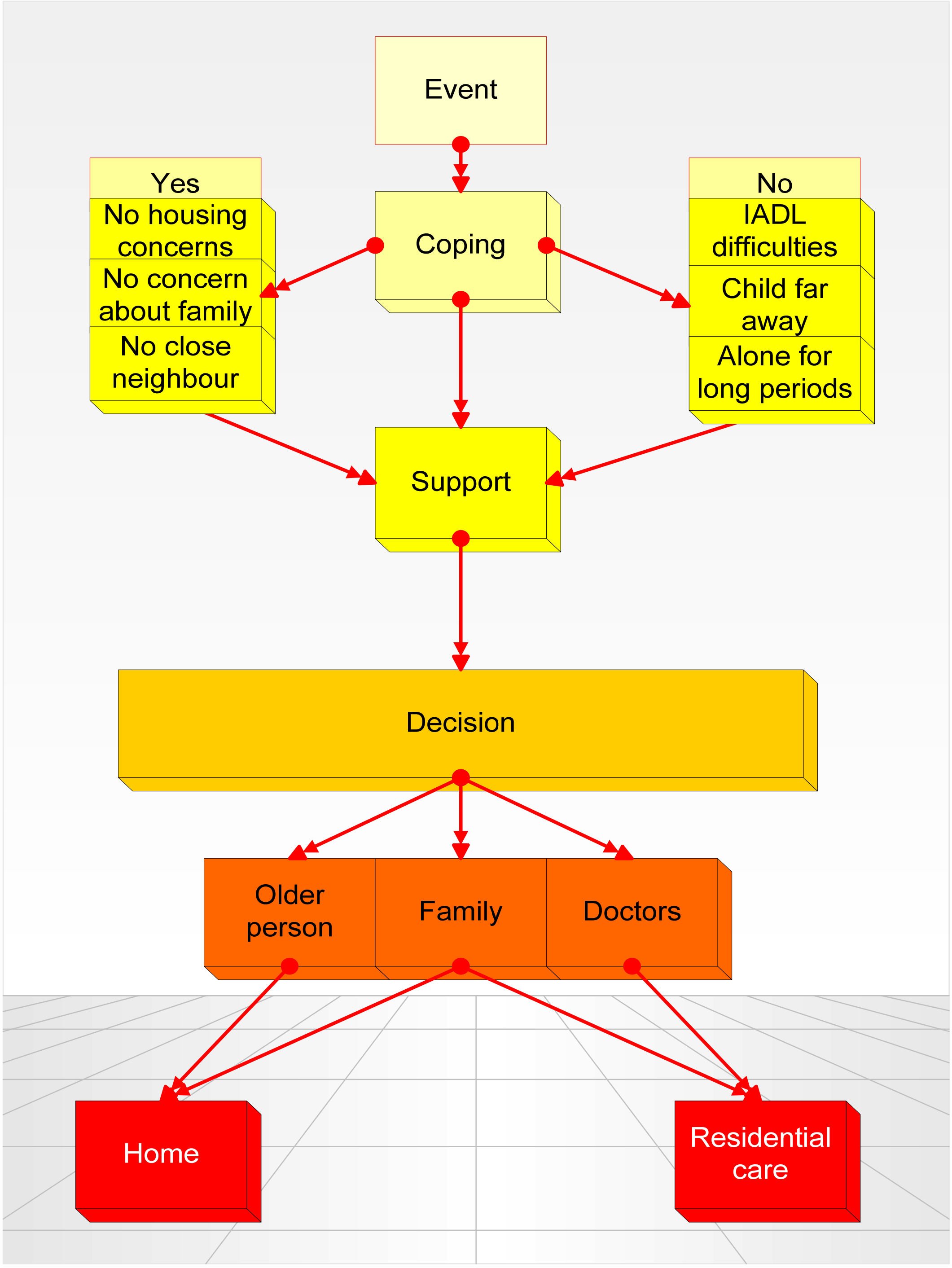
Figure 6.13: Comparison of caregiver stress

When looking at the qualitative findings and the quantitative findings, a model emerges which demonstrates the likely outcomes of the statistically significant variables, such as difficulties with activities of daily living and not having the support of a child to assist. It is interesting to find that not seeing a neighbour could increase the likelihood of remaining at home, as shown in the results of the regression analysis. It may be assumed, that people with high support needs, those most at risk of residential care entry, are more likely to call on their neighbours if their child is not living near. Those most likely to remain at home and therefore less likely to call on neighbours were the people needing the lower support. This assumption would need to be explored in further research There was a statistically significant correlation between having support from neighbours and a child living far away (τ = -0.159, p = 0.01). The other assumption which may be made is, in today's society in the big cities, people are less likely to be friendly with neighbours, with many at work, therefore, would only call on them in the cases of an emergency, which would be most likely in the higher support group.

The process in the final Model (Figure 6.1) begins with whether the older person can cope with the difficulties and disabilities they encounter. The significant variables point the way to an outcome for the older person (Figure 6.14). This then leads to the question of their support, and is that support adequate for the older person to maintain a safe lifestyle? The question of safety is one of the major considerations for the family and the doctor when deciding the future outcomes. Next it is the decision, and that depends to a large extent on who makes it. The final outcome differs to some extent; if the older people are making the decision they are much more likely to advocate for remaining in their own homes. If the doctors make it, they are more likely to tend toward residential care, while the family is equally split between the two options.

6.7: Summary of the findings

Many factors were significantly associated with where the older person was living. When placed in specific groups which allowed a relationship between the factors, the most significant factors from the ASPIRE study were: (i) having a child living far away; (ii) a high dependence, which was the inability to perform specific higher level daily living tasks, including: cooking, use of the phone, shopping, housework, financial management, medication, and transportation; (iii) the older person not being home alone for long periods had a positive relationship with living at home; and (iv) not seeing a neighbour increase the likelihood of the older person remaining at home. In OPERA the significant associations were: (i) a lack of concern about housing; and (ii) a lack of concern about the family care, which both increased the likelihood of the older person remaining at home. Any level of dependence with instrumental activities of daily living was likely to be associated with the older person having a similar degree of loss of cognitive skills.



IADL= Instrumental activities of daily living

Figure 6.14 Steps and likely outcomes in the Final Model

Caregiver stress was slightly increased at home as compared to when the older person was in residential care, and was linked with the older person's level of pain.

The themes described a sequential process which progressed from the older person coping with their disabilities, through the support they received, to their eventual settlement in either residential care or home. The person who substantially influenced the older person entering residential care was the doctor, while the older people themselves were most influential in their bid to stay home. Concerning those choices, most of the older people at home were happy, while most of the older people within residential care were unhappy.

Chapter 7

Discussion

> *Old age is not so bad when you consider the alternatives*
>
> Marcus Porcius Cato (the elder) (234BC-149BC)

Respect for the older person has moved a long way from the times when respect was thought unnecessary and they should all be cast into an almshouse (Markson & Hollis-Sawyer, 2000). But are we really enabling older people to live in the manner and way they choose, or are we still putting them in New Zealand's equivalent of the almshouse, residential care? The almshouses were created in or around the 10th century in Britain, and continue to the present day, usually of charitable status and with the aim of supporting the independence of their residents. Residential care within New Zealand is often subsidised support, in an institutional setting, which does not engender individualisation, or personal choice. Is this what the older person wanted, and if not why did they go into residential care? OPERA considered the following research questions:

(1) What are the factors which led an older person to permanently live in residential care?
(2) Who had the major influence in the decision regarding where the older person should live?
(3) Is the older person happy with the decision made about where they are living?

No other literature was found which compared the risk of entering residential care within New Zealand. Similarly, no other New Zealand literature was found which identified who were the decision-makers for the older person either staying at home or entering residential care after a support needs assessment. No other literature was found which explored the older person's satisfaction with the decision about where they would live. In light of the above, the relevant literature from other countries was used, where possible, for comparison with the New Zealand results found within this study.

Firstly, the discussion gives a brief comparative overview of the main risk factors for residential care entry most commonly found within the literature, and those found by this study (Table 7.1). Secondly, to relocate or not to relocate examines the findings in relation to recent literature under the four qualitative findings themes: which were: coping, support, decisions, and residence. Thirdly, the implications of the findings are discussed in relation to policy and practice. Lastly, the limitations of the study will be followed by opportunities for future research, conclusions and a summary of the main findings.

7.1: Brief comparative overview

Only one risk factor is common to both the recent literature and this study's findings. Table 7.1 shows the only similarity between the risk factors was the older person's increased dependence as measured by the Instrumental activities of daily living scale (IADL). Risk factors for residential care entry commonly mentioned in the relevant literature: age, being female and being of European descent, are all unchangeable, inevitable, and by themselves should not be considered a risk. It is the other secondary factors which are attached to age, for example, which should be considered as the risk for residential care entry, not age itself. The secondary factors could be, for example, loss of cognitive ability, or a high dependence on others for help with activities of daily living. The term 'caregiver not coping', as describe in the literature, has been designated by this study as caregiver stress. Interestingly, there was found to be no statistically significant difference, and only a small numerical difference between those caregivers with the older person at home or with the older person in residential care. However, there was a slightly higher stress level at the 12 and 18-month interviews for the caregivers who were looking after the older person at home.

Living alone was not considered a high risk for residential care entry within this study; however, being home alone for long periods, and a concern about the family's care, were considered risks. When a child lived far away this proved to be one of the highest risks of residential care entry for the older person, but the broader category of having a family living far away did not feature as significant. The significant concerns found for housing and family care pointed to a strong association with the person remaining at home.

Table 7.1: Significant risk factors for residential care entry

Risk factors most commonly found within the literature, in order of popularity	Risk factors found by this study in order of statistical significance
Age	Difficulty with daily living activities (IADL scale)
Difficulty with daily living activities (IADL or ADL scales).	Having a child living far away
Living alone	Being home alone for long periods
Caregiver not coping	A concern about housing
Being of European descent ('being white')	A concern about the family's care

IADL = Instrumental activities of daily living, ADL = Activities of daily living.

7.2: To relocate or not to relocate?

This section will compare the study findings with relevant literature, and illustrate the similarities and differences under the theme headings, firstly that of the ability to cope. It will progress through the four themes and conclude with the theme residence, the place where the older person was living.

The ability to cope

The ability for an older person to cope with the day-to-day living tasks was dependent on many factors and combinations of factors, such as personal health, family, support, and their feeling of how they could control their lives. A loss of confidence in their abilities to perform daily living activities, or the loss of their driving status may also add to the insecurity of the older person (Freeman, Gange, Munoz, & West, 2006; Taylor & Donnelly, 2006). However, one of the major factors for coping at home is the ability to perform the everyday living activities on a day-to-day basis, which equates to their level of independence or dependence. As the level of dependence on the IADL scale increased so did the chances of going into residential care. For every step on the IADL scale, the risk of going into residential care increased nearly three times (0 fully independent, to 21 totally dependent). It is interesting to note that research has found that residential care also dramatically increased the level of dependency in the activities of daily living in older people in Taiwan (Liu & Tinker, 2001), which could conceivably be similar for New Zealand. Coping was also influenced by the amount of support, both from the family and community, which assisted the older person. There was a significant statistical relationship between the amount of social support the older person received and the level of their coping skills. Similar results were found in a study of community dwelling people who attended a community centre; however, a comparison with this study cannot be made due to the differences in sample populations. It is thought that Greenglass's population attending a community centre were unlikely to require very high levels of support (Greenglass, Fiksenbaum, & Eaton, 2006).

Having family living near was found in the Mosgiel trial to be beneficial if the older person was to remain at home (Keeling, 2001). However, OPERA found that it was specifically having a child living near which was beneficial to the older person remaining at home, as opposed to the more generalised family. Having a child living far away increased the risk of residential care entry by approximately 30 percent for every step of the scale (0 living with the child to 5 where the child is 80 kilometres or more away).

Not being able to cope was one of the fears portrayed by the older person in the dialogues, and coping was found to be of statistical significance in its relationship with residential care. One qualitative study of 19 residential care residents was one of the few studies found which described the older person’s feelings about coping. It talked about older people who could no longer cope as being at ‘the end of the line’ with no choice other than residential care (Nay, 1995). One of the overriding comments when discussing residential care, from both the older people and the caregivers, was ‘there was no other option’. Structured dependency (Townsend, 1981), or not being able to cope on one’s own, has been described as a ‘society created dependency’ and a path which people follow to eventual dependence. However, the more realistic view is that of people’s changes in material circumstances and health problems, which decreased their coping abilities (Blane et al., 2004). The older people spoken to in OPERA strongly worded their concerns about coping. However it was the increased health problems which led to the inability to perform the higher functional activities of daily living, which ultimately decreased their ability to cope. Coping was not the cause, but the secondary effect of some other problem, usually health.

Loneliness was reportedly a high concern of older people (Devroey et al., 2002; Wolinsky et al., 1992), with the older adults becoming lonelier as time passed (Dykstra, van Tilburg, & Gierveld, 2005). In Britain 64 percent of residential care admissions were from people who lived alone (Bebbington et al., 2001). Being home alone and loneliness are not necessarily synonymous; however, the two did have a statistically significant relationship. OPERA’s findings concurred with the finding that social isolation is often associated with loneliness, but is not always the cause (Havens et al., 2004). These findings led to the assumption that some loneliness could be alleviated with more meaningful social interaction within the community. A lack of activities which engage the older person can also lead to a feeling of loneliness. Within OPERA the older people were more concerned about how they would cope on their own, rather than being lonely per se.

While people with high support needs have a much higher likelihood of being lonely than others (Havens et al., 2004), it was interesting that OPERA found that people with high support needs living at home were marginally lonelier than their counterparts in residential care. People living alone are reportedly more robust, but are also more at risk from poor health outcomes (Lichtenberg et al., 2003), and more at risk of residential care admission (Greene & Ondrich, 1990). OPERA's findings did not agree with this, but found that it was specifically the being home alone for long periods, as opposed to living alone, which made the older people more at risk of residential care entry. The risk for these older people of residential care entry increased by approximately 10 percent for every step of the scale. The scale was from 0 where the older person was not home alone at all, to 5 where they were home alone for most of the day. The reason for this could be extrapolated to the person living alone, being more robust, and having more mechanisms set in place to assist them with coping. The person home alone for long periods, say from early morning to night (for example, when the spouse comes home from work) is less able to cope during the day, because they are less likely to have set up coping mechanisms. On the other hand, being lonely was also found by others to be a risk of residential care entry (Russell et al., 1997), but was not found by OPERA to be a significant risk.

OPERA concurred with other studies (Friedman et al., 2005) by finding that highly dependent older people with loss of functional activities were most at risk of entering residential care. While Bauer's study (Bauer, 1996) agreed with this finding, the study was for the total older population, so the results could be different for a group of frail older people. OPERA's population was only the frail older people needing high levels of support, so this counteracts Bauer's supposition, by agreeing with the findings of Friedman et al (Friedman et al., 2005). Other secondary factors, such as excessive intake of alcohol, also interacted with the older person's existing condition to produce an even greater effect or disability (Khan et al., 2002). While OPERA did not test for alcohol intack, it did find that poor cognitive performance had a strong linear relationship with high dependence (measured on the IADL scale). Similar to the OPERA findings, another study (Lichtenberg et al., 2003) found that high dependence associated with poor cognition were the major predictors of the older people's inability to return home from hospital, especially if they were previously living alone. Cognition by itself was not found in OPERA to be a significant factor for entry to residential care. This differed from a recent study looking at assessment prior to residential care entry, which found cognitive impairment increased the risk of residential care entry (Clarkson, Venables, Hughes, Burns, & Challis, 2006). People with a high dependence were also found to have higher depression rates, but OPERA did not find that depression alone had a statistical relationship with residential care. On the other hand depression has been found to often precede the disability onset, and link to residential care entry (Lichtenberg et al., 2003).

Studies found that no particular characteristics of people with dementia would categorically lead them to residential care entry (Fisher & Lieberman, 1999); however, many people with dementia are in residential care (nearly 50% of all people with dementia in New Zealand) (*Dementia in New Zealand: Improving quality in residential care*, 2002). OPERA did not specifically research people with dementia, but did include people with cognitive skill loss, which included people with dementia. Cognitive performance was found to have a linear relationship with residential care at each interview. Also, OPERA found that (i) people with any level of IADL difficulties were likely to have some cognitive loss, and (ii) even though cognitive performance may not be the driver to place a person in residential care, most people who entered residential care had some level of cognitive loss.

How did the support assist or prevent residential care entry?

When discussing support, it was usually the family (caregivers), or outside paid support (support workers) who assisted the older person. It was unfortunate to see that caregiver stress was high on the list of risks for residential care entry within the literature (Oyebode, 2003; Ryan, 2000). Family ‘burnout’ is descriptive of the end stages of the stress (Retsinas, 1991). Often the stress was caused by not enough outside assistance to support the caregiver, which has been considered as one of the overriding factors for residential care entry (Dulmus & Rapp-Paglicci, 2005). OPERA found that even with the knowledge of which services were provided, and how to access the information about those services; the older people and caregivers considered that the correct amount (or type) of required help was often not being provided at home. This left the caregivers with the feeling there was '*no other choice*' other than residential care. Some caregivers complained about having no help with the night-time duties, leaving them worn out. Consistent with the OPERA findings, the need for after-hours workers, along with lack of provision of flexibility of hours, has been cited (Buhr et al., 2006; Power, 1989) as the cause of caregiver stress. This in turn led to residential care admission in the majority of those in Power's 1989 study. However, there was disagreement on this point, and it was proposed that it was the lack of the multigenerational families, where the children were not living with the older people, that hastened the older person's entry into residential care (Wolinsky et al., 1992). It is debatable whether it would be better for the caregiver to live with the person being looked after, or to live a little away. It would depend on the care required especially at night, and the compatibility of the family itself. Families were divided on which was the best option; some preferred to live with the older person and some preferred to live a little away, and to have their own space. There appears to be no right answers, because living with the older person in a multigenerational family may well increase the stress of the caregiver rather than decrease it.

Unlike the paucity of literature about the older person's feels of going into residential care, there is a plethora of writing about the caregivers' stress, choices and feelings, such as: "*Carers frequently experience considerable guilt and emotional turmoil*" (Nolan et al., 1996, p. 4).

Many studies regarding caregivers discuss 'placement' into residential care (Netten, Darton, Bebbington, & Brown, 2001), which demonstrates a certain powerlessness on the part of the older person. For some families, residential care is the result of an imbalance between the caregiver's resources (time and finances) and the support needs of the older person (Ryan, 2000). Caregivers (and older people) within OPERA often complained about their insecure feeling with regard to the support workers. Their comments ranged from; being worried whether the support worker would turn up, to knowing that the support worker was rushing with their tasks and often not staying the required length of time. A lack of money being paid to the support worker was mentioned by the caregiver and the older person as the reason the support workers were not doing their job properly, or as they (the older person or caregiver) expected them to. As well as the caregiver's resources, there was the added factor of the older person not wanting to be a bother to their family, and not causing them too much concern. This was a constantly repeated theme in the OPERA dialogues.

Who made the relocation decision?

Relocation is stressful for all people, but in the case of the older person relocation was often preceded by an event such as health deterioration, or the death of the family caregiver (Rosswurm, 1983). Relocation was in many cases found to happen more than once in an older person's later life, although 60 percent of the OPERA population had remained in their present homes for ten years or more. The first move was usually the downsizing from the family home to a smaller more manageable 'unit' with less garden to look after. OPERA found that the size of the garden was one of the most common reasons for the older person to downsize. The next move was to be nearer to the children, with the last and most traumatic move to residential care.

The decision to move into residential care was less often made by the older person, and more often by the doctor, either the general practitioner or the hospital doctor. Physicians rated quality of life first, families' wishes next, and the older person's wishes a poor third and of much lesser importance (Cohen-Mansfield & Lipson, 2003). This article agrees with OPERA's findings that there was a statistical significance between the doctors as decision-makers and residential care entry. Decision-makers and decision-making are paramount to the question of where the older person will eventually live; residential care or home. Firstly, it must be reiterated that choice and the freedom of choice are basic human rights. This includes the freedom for the older person to choose where they live. When each unique decision is made it must be balanced with the individual's rights, and potential risk of residential care entry (Cooney & Keyes, 2004). Discharge from hospital is often the time when the safety of the older person is raised and when the physicians are informed by the community and homecare staff that the older person is not safe for discharge(Cooney & Keyes, 2004). In their haste discharge planners often forget to incorporate the older person's preferences and values, by not including them in the discharge planning (Kane & Kane, 2001). The suggested solution is residential care, though this often has its own risks, and even unhappiness, as noted in the Results Chapter.

The older person is often confused, disoriented, and anxious in the unfamiliar surroundings of an acute hospital ward, so needs special consideration in order to participate in the decision-making (Nolan et al., 1996). Unfortunately few older people have involvement in the decision made at discharge, to enter residential care (Liu & Tinker, 2001). When others make the decision for the older person they are indicating that the person is incompetent. "*A judgment of incompetence is based on an assessment of an individual's ability to make a decision and carry out a plan*" (Cooney & Keyes, 2004, p. 26). During the rush to discharge, it is questionable whether this point is thought through fully. Decisions about the best type of care should be made separately from the best provision of care (residential care or home). It is interesting to compare the autonomy given to the younger person making the same decision, as opposed to the older person. The older person deserves the same opportunities as the younger person in the choice of where they live. The older person's safety, which is often the consideration prior to residential care entry, should be reconsidered to a position of managed or negotiated risk. This position has now gained popularity in the USA (Kane, Bershadsky, & Bershadsky, 2006).

The doctors' knowledge and preference for residential care, as opposed to home (community) care (as shown in the Results Chapter) is further demonstrated by two recent studies showing that: (a) no cases reported the physician as being the source of community based long-term care recommendations (Felix, Dockter, Sanderson, Holladay, & Stewart, 2006); and (b) both geriatricians and primary care physicians preferred skilled nursing-care (residential care) (R. Kane et al., 2006).

Potential barriers, such as lack of information and limited staff time (Beck et al., 2002; Doherty & Doherty, 2005) are examples of the difficulties that older people faced when making one of the major decisions of their life. A repeating statement by the older people in OPERA was that they couldn’t hear the doctor, or didn’t understand the nurse when the options were being discussed. Many stated that the doctors talked to their family rather than to them. Articles purport that the older person is rarely influential in the process of this decision-making (Bell, 1996; Edwards et al., 2003). OPERA also found that the common themes related during the interviews indicated that the older person had little, if any, say or choice in where they were going to live. This would corroborate the finding that few older people felt they had a real choice (Nay, 1995).

Surprisingly, by far the greatest majority (86%) of older people in this study, when specifically questioned felt that they had an influence in where they lived. Contrary to this, the Needs Assessment Service Co-ordination managers (NASC) and family indicated the family had the greatest influence in the decision, with the NASC managers also citing the doctors as having more influence than the older person. The recently concluded ASPIRE study found that the general practitioner groups, which had the decision-making facilities for referral to residential care or remaining at home, had a much higher proportion of people remaining in their own homes, than the usual NASC referral group (Parsons et al., 2006). However, along with other research (Cheek et al., 1999; Gallois & Callan, 1997; Nolan et al., 1996) and the regression analysis, OPERA found that the doctor was most influential in the residential care decision, and that the older person was most influential in the decision to stay at home.

Family also had an influence in the decision-making, as illustrated by the following case study. This case study showed how an older person’s entry into residential care, because of a family disagreement, led to the older person's anger about the lack of autonomy within residential care. Medications were given to control this anger, which also made her unsteady, and thus she ended up in a wheelchair and lost the ability to walk (Barrett, 2006). In this case the older person felt she would do as the family suggested, so in a way she was pushed to make a decision.

It is a moot point whether the older person actually had the final say, or whether someone else did. The most important point is that they understood the decision made, and that they felt they participated fully in that decision. From the percentages of older people living at home saying that they had the major influence, it would appear they felt that they understood the decision and participated. Unfortunately, the same is not true for those people living in residential care, where only half said they had the major influence. It is worrying that this number of people had other people make the decision for them, especially when it has been found that surrogates correctly answered the older person's wishes only 61 percent of the time (Mattimore et al., 1997). Being involved in the decision-making must impact on the degree of satisfaction the older person felt with that decision, settling in to possibly a new residence, and the satisfaction with the residence itself.

Residence; relocation or staying at home?

"*I guess you could say I am homesick*" (E.T.1070). This statement by an older person in residential care reflects the feelings of many of the people who have had to relocate, either to be close to a family member, to downsize their home, or move to residential care. There appeared to be only two genuine choices when an older person needed substantial support; staying at home in the community with support, or residential care. OPERA did not find, as other studies have found (Bebbington et al., 1995; Miller & Weissert, 2000) that prior hospitalisation was an important predictor of residential care entry. There was no significant relationship other than an indication that the longer the person waited after the support needs assessment, the more likely it was that their previous hospital admission, or going into hospital in the future, would also lead to residential care entry. There were only slightly more people who had had previous hospital admission in residential care than people living at home.

Three items: (i) older age, (Branch & Jette, 1982; Miller & Weissert, 2000); (ii) being of European descent (Bauer, 1996; Friedman et al., 2005); and (iii) being female (Liu & Tinker, 2001; Palmore, 1976) were often mentioned as being major predictors of residential care entry. However they are unchangeable, not an event or present process, and therefore should not be considered a ‘risk’ for residential care entry. Risk, by definition, is a potential harm which arises from some future event or present process (Deverson, 1997). For the purpose of defining the factors (risks) which are involved in an older person entering residential care, it is the other factors which are consequential. Being female or of European descent does not increase the risk of residential care, as suggested by some (Kersting, 1994), but is a consequence of the greater numbers within these two categories of the residential care population. This could merely be due to the greater numbers of females and people of European descent living within reach of a residential care institution. Cultural preferences are also a reason why people of non European descent are less often in residential care. Therefore, the rational for ‘being of European descent’ (or as the articles report ‘being white’) as a risk for residential care entry, is questionable. It is the way people with disabilities are coping, and the support they are receiving which is of consequence to the risks of residential care entry, not their age, gender or ethnicity. Just because most people in residential care are of European descent, older and female does not make their risk any higher than those, for example, with grey hair, smaller stature, or any other similarity, who happen to be in the majority within residential care.

Conversations with the older people, caregivers and the NASC managers did not suggest that age, being female, or being of European descent were of great concern. Some older people were resigned to the fact that they might have to go into residential care, but this was not because of age, but due to their not being able to cope for some other reason. None of these three factors correlated significantly with the dichotomous variable ‘residential care or home’. However, older age may have been considered a ‘risk’ due to the increasing likelihood of some disabling condition, or event rendering them unable to remain at home, as a person progressed further into older age.

The literature about the older person’s satisfaction did not specifically relate to a satisfaction with the decision to move to residential care, but related more to the older person’s satisfaction in general. However, this study looked specifically at the satisfaction with the decision surrounding where the older person lived after the support needs assessment. There was a diversity of opinions, from those who were happy to stay at home to those who were happy with residential care. Some people were just resigned to the fact that residential care ‘comes to everyone if you live long enough’. Overall few people stated that they were sad at home and would prefer residential care, but many people in residential care said they missed their home.

Surprisingly, when the older people were asked what change they would wish for, only one person mentioned going home (from a relative’s place), and no one in residential care wished the change to be to return home. A study of 60 older ladies who lived at home found that they seldom spoke of how their lives could be better, and just accepted what was their lot (Bearon, 1989). However, when comparing those people who lived at home with people in residential care, there was a trend of increased unhappiness as more people entered residential care.

The final model has now been developed to show the outcomes from OPERA. These include health service and policy implications and a decisional assessment tool (Figure 7.1). The health and policy implications as well as the decisional assessment tool will be discussed in the following chapter (Chapter 8).

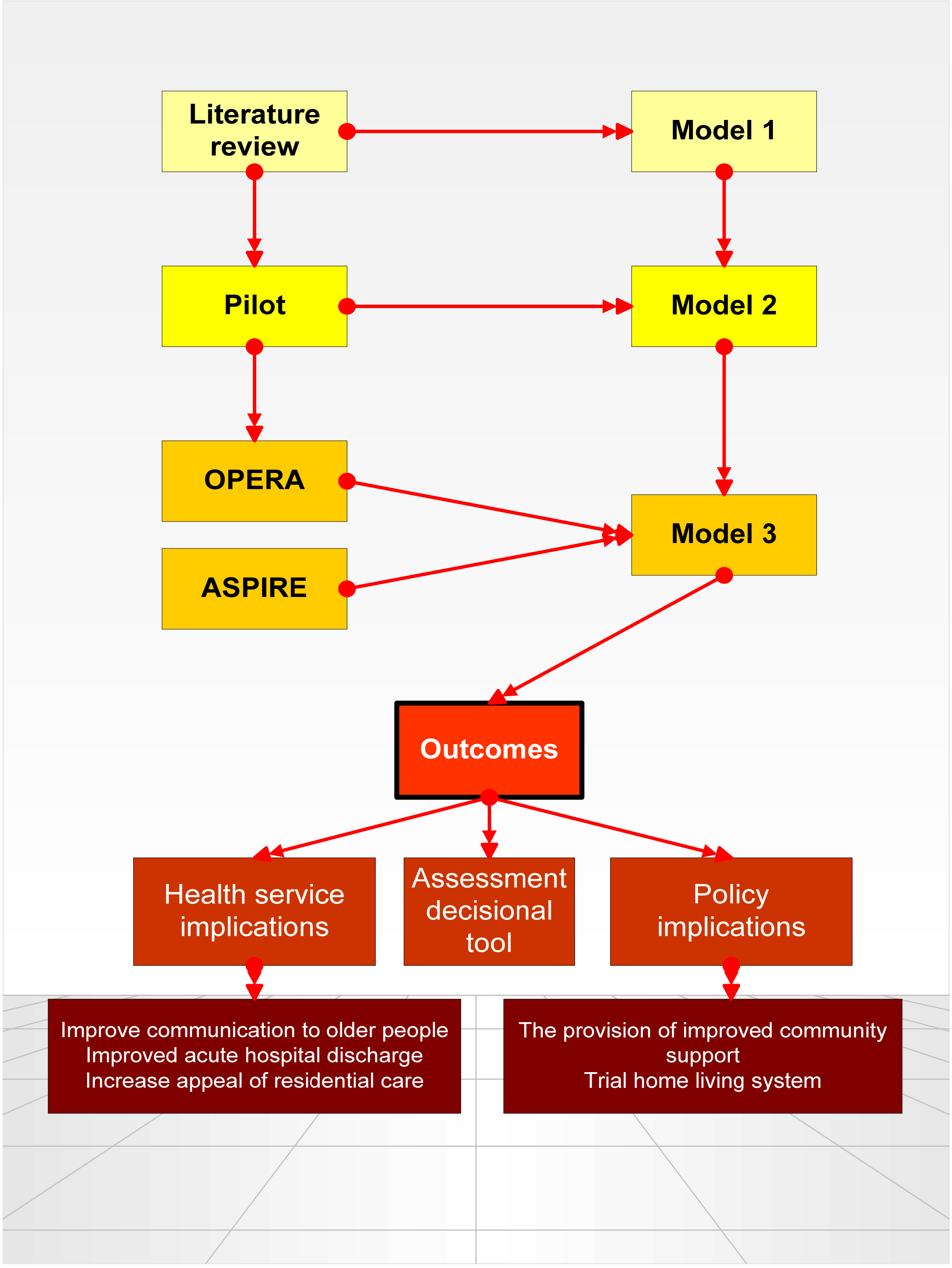


Figure 7.1 Final Model leading to the outcomes

7.4: Study limitations

The older people in this study were all exceedingly generous in giving their time freely without any form of rewards other than the opportunity to talk to the researcher. One of the difficulties with investigating the older people was their willingness to be helpful, and describe in detail all that had happened to them at many points in their life. While this was very interesting, it was also time consuming, and not altogether relevant to the topic being discussed. The older people were so obviously enjoying talking about themselves and their experiences that it was often difficult to keep them to the point without appearing to be uninterested in what they were relating. People in residential care were often reticent about saying anything negative about where they were living, or their decision to live in residential care, for fear of retribution by the staff. This may have inadvertently altered some of the answers to the satisfaction questions, although if this were the case the trends of the results would not alter significantly, but perhaps increase in negativity within residential care.

Consents

Being asked to sign a consent form could often appear threatening to an older person and could lead to considerable resistance, and even non-participation. The following illustrates the point: an older study participant agreed to participate in the study and talk about his experiences. However, when he was asked to sign the consent form, he appeared quite scared and refused to sign anything until all his relatives were there to see what he was signing. Research participation has been found to be enhanced by the use of oral consents with older people (La Rue & Markee, 1995). An oral consent may have enlisted more participants, as in the case of the above; however, it was felt to be safer from the point of view of the older person perhaps forgetting that they had given permission, to progress only with the written consents.

Recruitment

Recruitment in Christchurch and Hamilton was difficult due to having to rely on other researchers to explain the study and gain the written consent from the participants. The participants were all selected from the ASPIRE study after they had their initial ASPIRE interview. The questionnaires for ASPIRE took nearly an hour, so researchers were often hesitant to ask the older person to give any more time. The small number of participants from Hamilton made a comparison between the three research sites impossible.

Unfortunately there was a small percentage of older people who progressed into residential care. This may have been due to the research associates not selecting participants with the most severe disabilities.

There was a much smaller percentage of caregivers included than anticipated. Many of the older people from Christchurch appeared not to have caregivers, or the caregivers' names were not included on the recruitment form. This may have been due to the fact (as noted in the ASPIRE results) that overall they did not have such high support needs as the people in either Lower Hutt or Hamilton.

Selection and sampling bias

All the participants were recruited from ASPIRE, which only recruited older people with high or very high needs who passed through the Needs Assessment Service Co-ordination centres from the three cities. Since all the people within these two categories were invited to participate, ASPIRE considered it appropriate to make this distinction.

A sampling bias occurred particularly from Hamilton, where so few people were recruited for OPERA. People who were severely cognitively impaired or otherwise unwell were probably not asked to participate. A similar bias may have occurred from Christchurch, although not so marked. This was demonstrated when the OPERA population characteristics were compared with the ASPIRE sample characteristics. In most areas, the ASPIRE population were more dependent and had more disabilities. This sampling bias was counteracted by the total ASPIRE population data being analysed within the quantitative results of this study. There may have been a minimal bias (due to the phone interviews) against people living at home in Christchurch and Hamilton without a phone, although this has not been shown to be true.

Collection difficulties

Collecting data over three sites was challenging. People in Lower Hutt were all interviewed face-to-face, but due to the cost of travel and the off-site researchers' time, only the people within residential care in Hamilton and Christchurch had a face-to-face interview. People at home in those two cities were interviewed by phone from Lower Hutt. This was at times both difficult where there was a hearing impairment, and expensive (toll costs) due to the willingness of the older people to talk. The different forms of interviews could have caused some bias, although this was not demonstrated. Older people may have been more willing to talk to someone face-to-face than on the telephone, and vice versa. Although the researchers were trained in the techniques of the interviews, there may have been different body language and emphasis on different things from one to the other. However, the questions were structured to alleviate as much of this form of bias as possible.

Maturation over time

People change over time, which affects both their perception of where they are and their feelings about that place. Many things interact to form an overall impression of the situation at the time. Some of the satisfaction about the decision of where the older people were living could have been due to extraneous factors, rather than the decision itself. It was often difficult to portray the question as just the decision and not the final outcome of that decision. The satisfaction could change over time with the changing circumstances, such as getting used to the environment of residential care, or if at home the loss of a spouse leaving the partner alone. Both these situations could affect the perceived feelings about the decision made.

Money constraints

Involving people in research involves adequate resources, such as time and money (Mountain, 2003). This study was limited due to the cost of travelling to Christchurch and Hamilton to perform face-to-face interviews. It was also limited to the provision of the Hamilton and Christchurch researchers only having time to interview those people in residential care. Other than this, time was a constraint, due to the cost of the long distance telephone interviews.

Communication difficulties with the older person

When a person had difficulty answering the questions, often a caregiver (usually the daughter) would answer for the older person. As noted previously, it was found that not all surrogates answered the way the older person would wish, therefore the thoughts and comments of the older person may not have been reflected accurately when portrayed by their caregiver. A very small percentage of older people had other people answer for them.

Interviewee and interviewer effects

Due to the open non-standardised questionnaire, the following effects could have occurred: (i) the effects of the older people or their caregivers answering the questions in a specific manner because they were aware they were research participants; (ii) the attributes of the researcher, such as their experience, age, body language and specific profession. There was no evidence of a systematic bias from either the interviewee or the interviewer.

Data recording

The data from both OPERA and ASPIRE were collected by different people in each city. The researchers were all health professionals and trained in the specific details of both, OPERA and ASPIRE; however, differences may have occurred due to the differences in the researchers’ analysis of the situation at the time. This was minimised by frequent contact with the researchers throughout the study, and one person inputting all the final data. There was no evidence of bias within the recording of the data.

Data analysis

The data from OPERA were all coded and input in Lower Hutt, while the data from ASPIRE were input in Auckland, then transferred to Lower Hutt for cleaning, transferring from Excel to SPSS, and analysis. While the data from OPERA were transcribed verbatim, and entered into the computer system, the data from ASPIRE were handled by others and then transferred with explanations of coding. Every effort was made to ensure the data transfer was accurate between the sites.

ASPIRE trial

The ASPIRE trial was a randomized controlled trial with an intervention component, however, when the data was provided to the researcher the data was still blinded.

The unblinded information was not available to the author at the time of writing the thesis. There could be a possibility of future re-analysis of the ASPIRE data using the binary logistics regression when the intervention and control participants are known.

Chapter 8

Conclusions

> *O that a man might know the end of this day's business ere it come!*
> *But it sufficeth that the day will end, and then the end is known*
>
> William Shakespeare (1564-1616) (from Julius Caesar)

The discussion has sought to explore previous research which builds on to and adds meaning to the analysis within this study. The conclusions will summarise the main areas of interest in relation to the research questions. Lastly, the summary will itemise the major points.

What are the factors which led people to enter residential care?

The most significant factor which increased the risk of residential care was increased dependence caused by an inability to perform the activities of daily living (measured by the IADL scale). Alongside increased dependence sits the loss of cognitive performance, which has been shown to be highly associated with all levels of loss of function as measured by the IADL scale. This inevitably reduces the older person's ability to cope, which then leads to caregiver stress. Having a child living near and the older person not being home alone for long periods had a strong association with being able to remain at home. A high concern about housing and a concern about the care provided by the family and support services are also indicators for residential care entry.

Who had the major influence in the decision-making?

From the verbal reports, many of the older people felt that they did not understand what the doctor was saying, or even if there were options being offered. However, overall most of the New Zealand older people did feel that they had a major influence in the decision regarding where they would safely live. The older people living at home appeared to have been party to more of the decisions (90%)

than their counterparts in residential care (54%). The doctor's influence increased from 24 percent of those older people at home, to 53 percent of the people in residential care. The doctor's influence also had a strong statistical significance with residential care entry. The family, being the other group with a major influence on the decision, had a similar influence on both home and residential care decisions at 46-47 percent.

Is the older person happy with the decision made?

There was a dramatic change over the six-month period as more people entered residential care. At the initial interview, most people were living at home and most people were happy about the decision to live there. Also, more people in residential care were happy about the decision than unhappy. But by six months the positions had changed to an increased number of people being unhappy both at home and in residential care. The most striking factor is the similar percentages of people happy with the decision to live at home (71%) to the people unhappy with the decision to live in residential care (70%).

The findings in this study indicate a positive outcome for older people living at home who felt included in the decision-making, but there is work to be done to achieve a similar feeling amongst older people in residential care. The incorporation of more older people in the decision-making may well improve the satisfaction with the decision. The current investigation has demonstrated that a high dependence with Instrumental activities of Daily living (IADL scale), a child living far away, and being alone at home for long periods are major indicators for residential care entry.

8:1 Summary of key findings

The following is a list of the 13 most important findings of the study:

(i) Most older people (90%) felt they made the decision to remain at home.

(ii) Over half (53%) of the older people felt that the doctors made the decision for them to enter residential care.

(iii) The majority (73%) of the older people were happy with the decision to live at home.

(iv) The majority (71%) of the older people were unhappy with the decision to live in residential care.

(v) A high dependence score on the Instrumental activities of daily living scale was a major indicator of residential care entry, with a 30 percent greater chance with every step of the scale (0-21).

(vi) Having a child living far away increased the risk of moving to residential care by 30 percent for every step of the scale (0-5).

(vii) Being home alone for long periods increased the risk of entering residential care by 10 percent.

(viii) Being home alone for long periods was more statistically significant in relation to residential care entry than living alone, or being lonely.

(ix) Having little concern about housing increased the chances of remaining at home.

(x) Having little concern about the family care increased the chances of remaining at home.

(xi) Cognitive performance loss is likely to accompany any level of IADL dependence.

(xii) A person with high dependence is also likely to have depression.

(xiii) Caregivers complained of inadequate or inappropriate support.

8.2: Implications of findings for policy and practice

Every older person has the right to be in charge of their own destiny (Kapp, 1992), whether they choose to enter residential care or choose to remain at home. The Government's ‘Health of older people strategy’ would like all older people to be able to ‘age-in-place’. Research has shown that it is desirable for older people to exercise choice, and maintain an element of control (Nolan et al., 1996). Most older people find it preferable to stay in their own homes (Thorson, 2000). The older person, health authorities and the research all point in one direction, yet it appears that New Zealand is still not there yet. The older person still does not have a significant influence in the decision-making, particularly in regard to entering residential care, and the majority of older people are not happy with the decision to go into residential care.

Several changes could affect the outcome of the older person going into residential care, as seen in the Final Model (Figure 7.1), such as: (i) the improvement of communication to the older person; (ii) the provision of good support systems within the community; (iii) the reduction of the urgency of discharge after acute hospital admissions; (iv) the use of ‘trial home living’ with specialised support services; and (v) increase the appeal of residential care for the older person, in other words reduce the stigma surrounding residential care.

Communication to the older person

From the narrative reports of the older people, we know that many did not understand the need for them to enter residential care, nor did they understand the choices that could be made, or were made. It is not the decision itself which must be addressed, but the process towards that decision, by the set of alternatives proposed (Simonson & Tversky, 1992). An assessment decisional tool (Diagrammatic overview, Figure 8.1) may well assist the busy clinician (nurse, doctor, or other health professional) to ensure that the older person has fully understood all the implications surrounding the decision, and that the best decision is made. This would include areas such as the time factor for both the health professional and the older person, language, and the approach used, such as addressing the older person directly and not speaking through the family.

The community support system

The development of a more comprehensive support system within the community would require considerable funding, and in a climate of health rationalisation this funding is not always readily available. However, research (Retsinas, 1991; Ryan, 2000) and the narrative reports in OPERA have shown that residential care entry was often the result of a breakdown in support services. This could be the result of an inability to obtain sufficient help, or the correct support services, which forced residential care entry. Specific support services, which are specialised and particularly tailored for the needs of the individual, with adequate training and supervision, are warranted. More appropriate respite care to relieve the caregiver, particularly if there are night duties involved, could be offered. Respite care could entail a person coming in to live in the home for a specific period and taking over the responsibility from the family caregiver. Respite care could also be the older person being in a centre which supervises the nights and the older person going home during the day. There are many forms of respite care which could be tried, all tailored to the specific needs of the individual caregiver and the older person. Improved support services do not necessarily mean more time, but better utilisation of that time by specifically trained caregivers at appropriate times.

Acute hospital discharge

It is well known that the acute shortage and cost of hospital beds does not enable the hospital doctor to continue to approve the older person's stay within the acute hospital for long periods. Assessment, treatment and rehabilitation wards are functioning in most of the larger hospitals, but they have a limited time for the older person in which to accomplish all the skills required to return home. The older person, after suffering a stroke for example, is not necessarily going to have maximum recovery within the time of the hospital stay; therefore often the easiest option for the safety of the older person is residential care. The hospital discharge often entails the gathering of relatives, which leads to the need for quick action. Finding an available residential care service may over-ride the longer range considerations and unfortunately therefore, set the course for the subsequent care (Kane & Kane, 2001).

The Leeds Elderly Assessment Dependency Screening tool (LEADS) is an example of a tool which claims to be able to determine within two weeks of admission, the risk of residential care entry. LEADS identified 85% of the patients admitted to an acute ward who were at risk of residential are entry (Slade, Fear, & Tennant, 2006). Tools such as this would greatly assist the health professionals in their discharge planning, and enable more time for renovations at home. However, if the older person is not admitted to an Assessment, Treatment and Rehabilitation ward prior to discharge, their stay may not be long enough to benefit from this type of tool. The average length of stay in New Zealand hospitals is just over three days (Ministry of Health, 2006) which has decreased by five days from the 2001/02 figures (8.3 days) (New Zealand Health Information Service, 2004). These figures contain all patients, but do give an indication of the continued push to reduce the patients' time in acute hospital beds.

Another barrier to the older person returning home is the length of time taken for the home modifications to be done, such as ramps, rails, etc. With highly dependent older people having difficulties with daily living functions being the most at risk for residential care entry, it would be extremely likely that home alterations would be needed in these cases. An older person cannot go to a home which is unsafe; therefore it would seem practical for a specialised team to be funded specifically to do these alterations in an appropriate timeframe, prior to discharge. Adaptations and assistive technology (AT) have been described as site specific adaptations which include input from the older person (Lansley, McCreadie, & Tinker, 2004; McCreadie, Seale, Tinker, & Turner-Smith, 2002; Seale, McCreadie, Turner-Smith, & Tinker, 2002; Tinker, 2004). Of course some properties such as flats may not be suitable for adaptation, but within New Zealand the majority of houses would most likely accommodate some form of adaptation. This form of communicative site specific modification to the older person's existing home may enable more people to return home, and would be a cost effective way of providing the service (Lansley et al., 2004).

Trial home living

This is a combination of the suggestions above where a specialised team rehabilitates the older person in their own specifically tailored home, so that they can reach full potential without the need for residential care. Within residential care, the caregivers are trained to ‘care’ for the person to the best of their abilities. This often means, for example, dressing the older person, because there was not time to wait for them to do it themselves. Unfortunately, due to many issues within residential care, the caregivers did not have time to rehabilitate the older person, and indeed ‘cared’ for them instead. This inevitably led to the older person’s increased dependence on the residential care staff. The older person is more confused in the unfamiliar surroundings of residential care, and becomes more unsure and dependent on others for assistance and advice.

The alternative of a trial of home living would give the older person a familiar environment and specialised rehabilitation tailored to their individual needs. This would provide time for recovery, specialised training, and an environment which was both familiar and safe for the older person. Examples of home rehabilitation would be the Community FIRST programme, which was proved effective by the ASPIRE trial, or the Promoting independence programme also trialed by ASPIRE.

Increased appeal of residential care

Some people who decided to live in residential care were happy with the attention they received, but others were not. Some spoke of being lonely and having to do things at times that were not what they were used to; in other words institutional living. Residential care could, with more funding (allowing for more staff), provide more choice of meal times (meals are often the highlight of the older person’s day). Also better options for socialisation, but most importantly treat the person with respect and as an individual who has the right to choose. The older person could be made to feel useful and assist with some of the day-to-day tasks, and have some responsibility. Most women have had a lifetime of dusting and cleaning, so could assist in these areas, especially within their own rooms, which, contrary to hospital requirements, do not have to be ‘sterile environments’ with everything highly polished and in its place. A move away from the medical model would certainly assist this to happen, such as a ‘consumer-focused’ social model (Mitty & Clark, 2003). In the social model there would be discussions around the self-medication, self-determining and self-directing rights. Older person, goal-oriented rehabilitation would also enhance the older person’s existence within residential care. In summary, the environment within residential care could be tailored more to being 'consumer-focused' and less towards hospital-type care ('hospital treatments').

8.3: Future research

There is scope for many research projects within the older population groups, to assist the older people, their caregivers, and the policy makers. With the projected explosion of the older population group, rational, cost-effective and customer-focused services would seem to be essential for the future.

Social model residential care.

There are some people who will always have to be or choose to live in residential care. For those people it would improve their quality of life if they had an environment in which they felt they had some control. It has been shown by OPERA that most people are not happy with the decision to go into residential care. At present there are few if any truly 'consumer-focused' residential care facilities. Therefore a trial of other types of residential intensive support, such as a non-medical model environment, would be beneficial.

A day in the life of people with high support needs.

Does the life of a very dependent older person change when they enter residential care? Are they doing anything which is different, and if so what? What are the positive aspects of living at home with high support, and what are the positive things about living in residential care? Can the good things from both be combined to improve the quality of life for older people? Research could compare 20 older people living at home with 20 living in residential care, on a daily basis over one month. This could be done by asking the older person to keep a diary of what happens to them throughout the day.

The decisional tool

To assist the health professionals to include and inform the older person, the researcher developed a decisional tool (Figure 8.1) for use by either the key worker for the older person, or by another member of the Multidisciplinary team. The tool should be used in conjunction with other assessment procedures.

To study the effectiveness of the decisional assessment tool to ascertain its effectiveness in: (i) enabling the older people are well informed and of the choices available and fell that hey have participated in the discharge decision making; (ii) the health professionals being sure that they have both informed and included the older people in the decision making; (iii) demonstrating that the process using the decisional tool is cost effective; (iv) more older people being able to remain within their own homes.

To achieve these aims the tool would be the responsibility of the key worker for the older person. The key worker is a member of the multidisciplinary team (MDT), and included when family meetings or discharge planning meetings are planned, prior to the older person's discharge. The decisional tool will act as a trigger for each step of the consultation process between the MDT and the older person. If a key worker is not available an advocate, such as, a social worker or religious leader could be used to discuss the discharge information and options with the older person.

8.4 Summary of policy implications and future research

Policy implications

(i) Better communication to the older person both at home and in acute hospital.

(ii) Improved community support for the older person and the caregiver.

(iii) Acute hospital discharges. The urgency of discharges needs to be addressed.

(iv) Adopt a trial home living system with all supports in place prior to residential care entry.

(v) Increase the appeal of residential care for the older person.

Future research

(i) Investigate a social model of residential care where the older people have more choice

(ii) Compare the lives of older people at home and in residential care

(iii) Trial a decisional tool which assists the information given to and choices made by the older person.

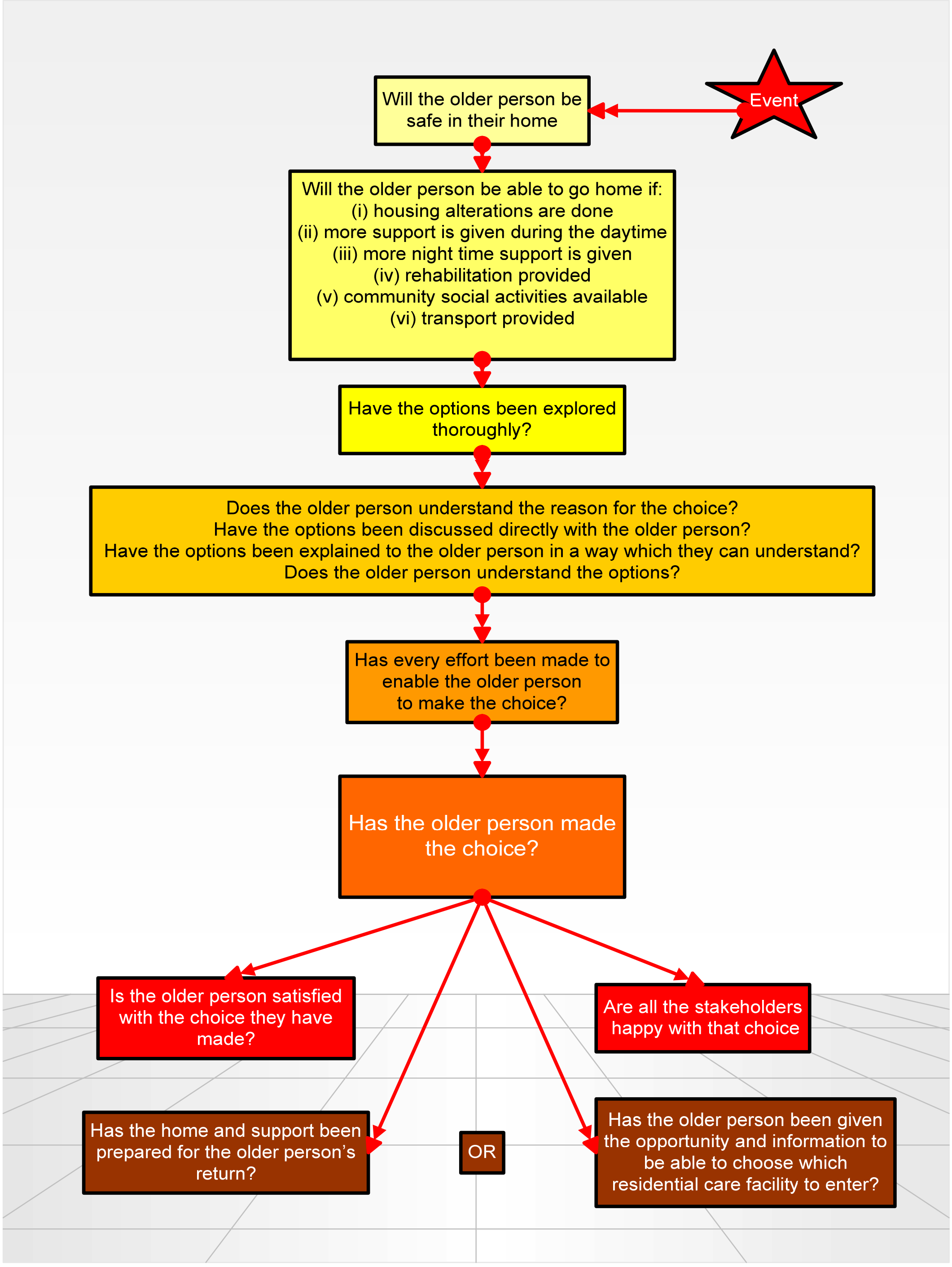


Figure 8.1: Decisional tool

Appendices

Table A.5.1: Pilot information sheet for older people in residential care

THE UNIVERSITY OF AUCKLAND
NEW ZEALAND

OPERA

Older people entering residential accommodation

Pilot information sheet

Introduction

The OPERA study will be looking at the reasons and decisions made surrounding an older person's admission to a rest home or continuing care hospital. It is hoped that from this study future older people and their caregivers will have a better understanding of the processes that are involved. This understanding will allow them to have greater knowledge of the processes and a real choice of where they want to live. It is hope that the study will also assist with the decisions of how best to distribute funds to support these services.

Within the OPERA study there is going to be a questionnaire designed to be given to all older people who are assessed as needing health and disability support in the future. I t is planned to commence using this questionnaire in the middle of 2004 in Lower Hutt, Christchurch and Hamilton (approximately 100 people).

The purpose of the Pilot

The OPERA study is in two parts (1) a pilot and (2) the main study. The pilot is the interview which we are asking you to participate in now. It is to assist with the development of the questionnaire for the main study.

How many people are involved in the pilot?

There will be approximately 12 older people from Lower Hutt selected to assist with the pilot.

What is involved?

If you decide that you would like to take part in the pilot you will have one interview with the Research Fellow, which could take up to one hour. You will also be asked for the name of your primary informal caregiver (e.g. family member or friend). You will be asked if you have any objection to the Research Fellow talking to them, to discuss the process of your move to the rest home, from their perspective.

Where will the interview be?

Where ever you are living at the moment.

What will the interview be about, what sort of questions will be asked?

You will be asked about what happened prior to your move to a rest home and questions around how you felt about the decision and how the process of making that went.

Confidentiality

All the data collected from the interview will be held in the strictest confidence without reference to your name. It is very important that the data is correct, so to enable accuracy you will be asked if you mind a tape recorder present at the interview. The information will be kept in a locked cabinet and will be kept for the duration of the OPERA study (4 years) then destroyed.

Withdrawal from the interview

You may conclude the interview at any time you wish and you do not have to have a reason for doing so, as participation is voluntary.

Approval

The OPERA study has approval from the Auckland Ethics Committee on behalf of the Waikato, Wellington and Canterbury Ethics Committees.

Further information

You are encouraged to ask questions at any time during the interview.

If at any time you want more information on the pilot you may call Diane Jorgensen (Research Fellow) on 04 5637435 or Dr Matthew Parsons (Senior lecturer, School of Nursing Auckland) on 09 373 7599.

About the Researcher

Diane Jorgensen is a trained health professional who has had many years experience working with older people in New Zealand and overseas.

In formation sheet adapted from the ASPIRE information sheet

A similar information sheet was produced for those older people living at home

Table A.5.2: Pilot questionnaire for older people living in residential care

Older people’s questions	Probes
What happened prior to your move here	Tell me about anything that happened to you in the last month that differed from the month before.
Tell me about the decision for you to move into residential care	Did you have a meeting with your family and another group of hospital workers? Tell me what I would have heard had I been at that meeting.
Tell me about the rest home and yourself now	Things will be different here from where you were before, can you tell me about how you feel now?
Tell me about your family and friends	Describe your family, friends and how are they feeling now?
Is there anything that you want to add about the reasons you moved into residential care?	

Table A.5.3: Pilot questionnaire for older people living at home

Older people's questions	Probes
Tell me about what has happened to you in the last month	Tell me about anything that happened to you in the last month that differed from the month before.
Have there been any changes which might influence whether you continue to live in your present home here?	Did you have a meeting with your family and another group of hospital workers? Tell me what I would have heard had I been at that meeting.
Tell me about yourself now	Things may be different now from before the assessment, can you tell me about how you feel now?
Tell me about your family and friends	Describe your family, friends and how are they feeling now?
Is there anything that you want to add about the reasons you moved into residential care?	

Table A.5.4: Pilot questionnaires for the NASC and MDT

Questions	Prompts
What do you consider to be important features of discharge planning and permanent placement for older people?	General categories in the placement decision: people involved, information available, factors, triggers, outcomes for the older people, family and health professionals.

NASC = Needs Assessment Service Co-ordination, MDT = Multi-disciplinary team

Table A.5.5: Older people's consent form

THE UNIVERSITY OF AUCKLAND
NEW ZEALAND

OPERA

Consent Form

Older People Entering Residential Accommodation

Contact: Diane Jörgensen A sub-study of ASPIRE

Ph: 04 5636435 or 027 223 6280

I,……………………………………… acknowledge that I have had explained to me by the Researcher , the nature and procedures involved with this research study.

English	I wish to have an interpreter	Yes	No
Maori	E hiahia ana ahau ki tetahi kaiwhakamaori/ kaiwhaka pakeha korero	Ae	Kao
Samoan	Oute mana'o ia iai se fa'amatala upu	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea	Io	Ikai
Cook Island	Ka inangaro au I tetai tangata uri reo	Ae	Kare
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupo	E	Nakai

I have read and I understand the information sheet dated 31st August 2004 for volunteers taking part in the study designed to evaluate entry into residential care. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whanau support or a friend to help me ask questions and understand the study.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the session at any time and this will in no way affect my continuing health care

I have had this study explained to me by the Research assistant.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I have agreed to the Research Fellow talking about my placement with my primary caregiver and the medical team (including where appropriate the general practitioner, hospital multi-disciplinary team, and Needs Assessment Co-ordination Service).

I have had time to consider whether to take part in this study.

I know whom to contact if I have any problems from taking part in the study

I know whom to contact if I have any questions about the study.

I consent to take part as a participant in this study.

Signature (or proxy) ……………………………………………….. Date:

Form adapted from ASPIRE

A similar consent form was used for the Pilot and the caregivers

Table A.5.6: Older people’s OPERA information sheet

THE UNIVERSITY OF AUCKLAND
NEW ZEALAND

OPERA

Older people entering residential accommodation

Information sheet A sub study of ASPIRE

You are invite to take part in a research study as part of the ASPIRE trial, to look at placement decisions, and the factors involved in that decision. Taking part is voluntary (your choice).

What is the purpose of the study?

The OPERA study will involve approximately 100 older people living in Hamilton, Wellington and Christchurch. You have been selected for this study as you are part of the ASPIRE trial, and currently or are soon to receive health and disability support services for your care. The aim of this study is to have a better understanding of the processes and decision-makers who are involved in placement, so that future older people and decision-makers can be better informed.

What is involved?

If you decide that you would like to take part, you will undergo an interview which will be approximately 15 to 20 minutes, at your home, or in residential care, with a researcher who is a health professional. You will be asked about the control you feel you have over your decisions, about the amount of help and family support you have, who helped you with the placement decision and whether you are happy with that decision.

You will be asked to provide a further short interview (maximum 10 minutes) with the researcher after 6 months, to ask similar questions about your support and decision. We will also be asking similar questions from the caregiver who provides you will the most support, the Needs Assessment Service Co-ordination (NASC) manager and the Hospital multidisciplinary team, if appropriate.

What is being evaluated?

When a person is assessed by the NASC as needing high levels of health and disability support there are often decisions made about where the person is able to, or should live, for example residential care or at home. It is this placement decision, who makes it and what are the factors involved in that decision that this study is looking at. Factors could include for example, medical conditions, falls, or no one at home to help all make living at home difficult without help.

What are the expected benefits?

You may not directly benefit from the study. However you will help the people who fund, provide and deliver health services to older people in the community understand the placement decision, and factors which influence that decision.

What are the potential risks and discomforts?

As we are only asking questions there are no risks with this study. You will continue to receive care from your doctor, and other health services in your area. Your care will not be compromised or reduced because you have agreed to be part of this study.

Confidentiality

All data generated from this study will be treated with utmost confidentiality without reference to your name. It is very important that the data collected are accurate and therefore it will need to be checked against your medical records. You are therefore asked to give permission for the regulatory health authorities, and other relevant authorities to look at your medical records to help them carry out these checks. Naturally, the information will be kept strictly confidential and will be used only for statistical purposes of this study. Your identity will be kept confidential. In the study documents you will only be identified by your initials and a study number. The data will be kept for the duration of the study in a locked cabinet in the researcher's office in Lower Hutt, and destroyed in accordance with national research guidelines.

Withdrawal from the Study

Your participation in the study is entirely voluntary. You may with draw at any time, and you do not have to give a reason for doing so, although it would be helpful if you did, and participated in the final assessment visit if at all possible. Your doctor may also suggest that you withdraw if he/she has any concerns about your participation. You may also be withdrawn if you are not able to comply with the study procedures, or for other administrative reasons. If you do withdraw, this will in no way affect any future treatment you may require.

Approval

The OPERA study has approval from the Auckland Ethics Committee on behalf of the Waikato, Wellington and Canterbury Ethics Committees.

Compensation for physical injury

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assed by ACC according to the provisions of the 2002 Injury Prevention Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators.

If you have any questions about ACC, contact your nearest ACC office or the investigator.

Further information

You are encouraged to ask questions at any time during the study. If you have any questions at any time during the study please do not hesitate to ask your general practitioner or the research staff associated with the study. If you have queries or concerns regarding your rights as a participant in this study you may wish to contact a Health and Disability Advocate on 0800 423638. You will receive a copy of this information sheet.

If you want more information on this study, please contact Diane Jorgensen, Research Fellow on 04 5636435 or Dr Matthew Parsons Senior Lecturer School of Nursing 09 373 7599 ext. 83033

Adapted from the ASPIRE information sheet

Table A.5.7: Older people's questionnaire

QUESTIONNAIRE FOR OLDER PEOPLE **OPERA**

Hamilton	Lower Hutt	Christchurch

Date of interview…………….

Participant number ………………

SECTION ONE

Q1	Tell me about what you know of community help.

Q2	Tell me about your family involvement.

		5	4	3	2	1
Q3	The following questions are about how much control you feel that you have over your life	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
a	I can influence many of the things that happen to me					
b	I am confident I can solve most of the problems I have					
c	I can do just about anything if I am determined enough to do it					
d	What happens to me in the future mostly depends on me					
e	Sometimes I feel that I am being pushed around					

		5	4	3	2	1
Q4	Do you worry about your family doing too much?	Never	Hardly ever	Sometimes	Often	Very often

		5	4	3	2	1
Q5	Do you feel that you are causing them too much concern?	Never	Hardly ever	Sometimes	Often	Very often

		5	4	3	2	1
Q6	Were you given any other alternatives of where you could live?	Residential care	With my family	In own home	In a retiement village	No

		5	4	3	2	1
Q7	Do you worry about money?	Never	Hardly ever	Sometimes	Often	Very often

		5	4	3	2	1
Q8	What influence did money have on where you would live	Very strong influence	Strong influence	Small influence	Minimal influence	No influence

		5	4	3	2	1
Q9	Did any of the following people have an influence on where you are living now?	Very strong influence	Strong influence	Some influence	Minimal influence	No influence
a	Geriatrician					
b	Hospital Nurse					
c	District Nurse					
d	Social Worker					
e	Occupational therapist					
f	Physiotherapist					
g	General Practitioner					
h	Practice Nurse					
I	NASC					
j	Friends					
k	Family					
l	Myself					

Q10 Tell me about that decision

		5	4	3	2	1
Q11	Do you feel happy or sad about the decision of where you are living?	Very happy	Happy	No strong feeling	Sad	Very sad

Q12 If there was one thing that you could change what would it be?

SECTION TWO **Only for those participants living in the community**

		4	3	2	1
Q13	Are there concerns at home which would stop you staying there?	Strongly concerned	Moderately concerned	Minimally concerned	Unconcerned
a	Fear of falling				
b	Fear of burglary				
c	Housing				
d	Environmental aspects				
e	People at home				
f	My inability to cope				
g	Loneliness				
h	Personal hygiene				
I	Personal health				
j	Shopping				
k	No support from the community				
L	No close family				
m	Other				

SECTION THREE **Only for those participants living in residential care**

		4	3	2	1
Q14	What were the concerns at home which stopped you staying there?	Strongly concerned	Moderately concerned	Minimally concerned	Unconcerned
a	Fear of falling				
b	Fear of burglary				
c	Housing				
d	Environmental aspects				
e	People at home				
f	My inability to cope				
g	Loneliness				
h	Personal hygiene				
I	Personal health				
j	Shopping				
k	No support from the community				
L	No close family				
m	Other				

		5	4	3	2	1
Q15	If all the support you need was provided where ever you wanted, where would you rather be now?	Residential care	Living with my family	In my own home	Hospital	Other

Reversed questions were Q3e, 8, 13, and 14.

Table A.5.8. Caregiver's questionnaire

OPERA QUESTIONNAIRE FOR THE PRIMARY CAREGIVER

Hamilton	Lower Hutt	Christchurch

Date of interview…………….. **Participant number ………………**

SECTION ONE

Q1 Tell me about what you know of community help.

Q2 Tell me about what happened after the older person was assessed as needing care

		5	4	3	2	1
Q3	Did any of the following people influence the decision of where the older person should live?	Very strong influence	Strong influence	Some influence	Minimal influence	No influence
a	Geriatrician					
b	Hospital Nurse					
c	District Nurse					
d	Social Worker					
e	Occupational therapist					
f	Physiotherapist					
g	General Practitioner					
h	Practice Nurse					
I	NASC					
j	Friends					
k	Family					
L	The older person					

Q4 Tell me about that decision

Q5 Do you feel there were any other alternatives if so what were they?

		5	4	3	2	1
Q6	How do you feel about the decision?	Very happy	Happy	Relieved	Sad	Very sad

		4	3	2	1
Q7	Money influenced the decision of where the older person would live.	Strong influence	Moderate influence	Minimal influence	no influence

For primary care givers of a community resident please go to Section Two
For primary care givers of a residential care resident please go to Section Three

SECTION TWO **Only for caregivers of community residents**

		4	3	2	1
Q8	Are there concerns at home which would stop the older person staying there?	Strongly concerned	Moderately concerned	Minimally concerned	Unconcerned
a	Fear of falling				
b	Fear of burglary				
c	Housing				
d	Environmental aspects				
e	People at home				
f	Their inability to cope				
g	Their loneliness				
h	Their personal hygiene				
I	Their health				
j	Shopping				
k	No support from the community				
L	No close family				
m	Other				

SECTION THREE **Only for caregivers of residential care residents**

		5	4	3	2
Q9	What were there concerns at home which stopped the older person staying there?	Strongly concerned	Moderately concerned	Minimally concerned	Unconcerned
a	Fear of falling				
b	Fear of burglary				
c	Housing				
d	Environmental aspects				
e	People at home				
f	Their inability to cope				
g	Their loneliness				
h	Their personal hygiene				
I	Their health				
j	Shopping				
k	No support from the community				
L	No close family				
m	Other				

Reversed question, Q7.

Table A.5.9: Multi-disciplinary team questionnaire

SURVEY FOR THE MULTI-DISCIPLINARY TEAM

Hamilton	Lower Hutt	Christchurch

Date of interview……………..

Participant number ………………

		5	4	3	2	1
Q1	Which people are involved in the multi-disciplinary team meetings?	Doctor	Nurse	Occupational therapist	Physio therapist	Social worker
		10	9	8	7	6
		Domiciliary staff	NASC	Family	The older person	Other

		5	4	3	2	1
Q2	How experienced do you feel the team is in making discharge and support needs decisions?	Very experienced	Experienced	Somewhat experienced	Inexperienced	Very Inexperienced

		5	4	3	2	1
Q3	Does the team discuss the support needs with the older person?	Never	Hardly ever	Sometimes	Often	Very often

		5	4	3	2	1
Q4	Does your team make suggestions for placement?	Never	Hardly ever	Sometimes	Often	Very often

		5	4	3	2	1
Q5	Does the team inform the older person when going home should not be an option?	Never	Hardly ever	Sometimes	Often	Very often

		5	4	3	2	1
Q6	If so who informs the older person?	Doctor	Nurse	Occupational therapist	Physio therapist	Social worker
		10	9	8	7	6
		Domiciliary staff	NASC	Family	GP	Other

		5	4	3	2	1
Q7	Would you consider any of the following to be mandatory for placement within residential care	Never	Hardly ever	Sometimes	Often	Very often
a	No family					
b	Environmental hazards					
c	Patient depression					
d	Dementia					
e	Co-morbid medical condition					
f	Their fear of falling					
g	Their personal safety					
h	Decreased level of ADLs					
I	Positive attitude to residential care					
j	Other					

Table A.5.10: Needs assessment service co-ordination questionnaire

OPERA	**SURVEY FOR THE NASC**	Hamilton	Lower Hutt	Christchurch

Date of interview…………………………………… **Participant number ………………..**

		5	4	3	2	1
Q1	How experienced do you feel the team is in making placement decisions?	Very experienced	Experienced	Somewhat experienced	Inexperienced	Very inexperienced

		5	4	3	2	1
Q2	Does the team discuss the placement decisions with the older person?	Never	Hardly ever	Sometimes	Often	Very often

		5	4	3	2	1
Q3	Does the team inform the older person when going home should not be an option?	Never	Hardly ever	Sometimes	Often	Very often

		5	4	3	2	1
Q4	Would you consider any of the following to be mandatory for placement within residential care	Never	Hardly ever	Sometimes	Often	Very often
a	No family					
b	Environmental hazards					
c	Patient depression					
d	Severe Dementia					
e	Co-morbid medical condition					
f	Their fear of falling					
g	Their personal safety					
h	Decreased level of ADLs					
I	Positive attitude to residential care					
j	Other					

s are specifically about #………. Patient's name.

		5	4	3	2	1
Q5	What was the major influence on the placement decision?	No family	Environment hazards	Dementia	Medical condition	Fear of falling
		10	9	8	7	6
		Personal safety	Decreased level of ADLs	Positive attitude to resthome	Home care available	Very good home situation

		5	4	3	2	1
Q6	Do you feel that the older person was happy with the outcome of the NASC meeting?	Very happy	Happy	Relieved	Sad	Very sad

		5	4	3	2	1
Q7	Do you feel that the closest family member was happy with the outcome of the NASC meeting?	Very happy	Happy	Relieved	Sad	Very sad

		5	4	3	2	1
Q8	Did any of the following people influence the decision of where the older person should live?	Very strong influence	Strong influence	Some influence	Minimal influence	No influence
a	Geriatrician					
b	Hospital Nurse					
c	District Nurse					
d	Social Worker					
e	Occupational therapist					
f	Physiotherapist					
g	General Practitioner					
h	Practice Nurse					
I	NASC					
j	Friends					
k	Family					
L	The older person					

Q9	Tell me about anything else which was a factor in the placement decision?	

The following questions are specifically about #……….. Patient's name.

	5	4	3	2	1
Q8 What was the major influence on the placement decision?	No family	Environment hazards	Dementia	Medical condition	Fear of falling
	10	9	8	7	6
	Personal safety	Decreased level of ADLs	Positive attitude to resthome	Home care available	Very good home situation

	5	4	3	2	1
Q9 Who discussed the future with the older person?	Doctor	Nurse	Occupational therapist	Physio therapist	Social worker
	10	9	8	7	6
	Domiciliary staff	NASC	Family	GP	Other

	5	4	3	2	1
Q10 Who discussed the future with the older person's family?	Doctor	Nurse	Occupational therapist	Physio therapist	Social worker
	10	9	8	7	6
	Domiciliary staff	NASC	Family	The older person	Other

	5	4	3	2	1
Q11 Do you feel that the older person was happy with the outcome of the teams meeting?	Very happy	Happy	Relieved	Sad	Very sad

	5	4	3	2	1
Q12 Do you feel that the closest family member was happy with the outcome of the teams meeting?	Very happy	Happy	Relieved	Sad	Very sad

		5	4	3	2	1
Q13	Did any of the following people influence the decision of where the older person should live?	Very strong influence	Strong influence	Some influence	Minimal influence	No influence
a	Geriatrician					
b	Hospital Nurse					
c	District Nurse					
d	Social Worker					
e	Occupational therapist					
f	Physiotherapist					
g	General Practitioner					
h	Practice Nurse					
I	NASC					
j	Friends					
k	Family					
L	The older person					

Table A.5.11: SPSS formulae to calculate impairment

0 =	(303 = 0 OR 303 = 4) & (302 = 0) & (307 = 0)
1=	(303 = 1 OR 303 = 2 OR 303 = 3) & (302 = 0) & (307 = 0) OR (302 = 1) & (303 = 0 OR 303 = 4) & (307 = 0) OR (307 > 0) & (303 = 0 OR 303 = 4) & (302 = 0)
2=	(303 = 1 OR 303 = 2 OR 303 = 3) & (302 = 1) & (307 = 0) OR (303 = 1 OR 303 = 2 OR 303 = 3) & (307> 0) & (302 = 0) OR (302 = 1) & (307 > 0) & (303 = 0 OR 303 = 4)
3=	(303 = 1 OR 303 = 2 OR 303 = 3) & (302 = 1) & (307 > 0)

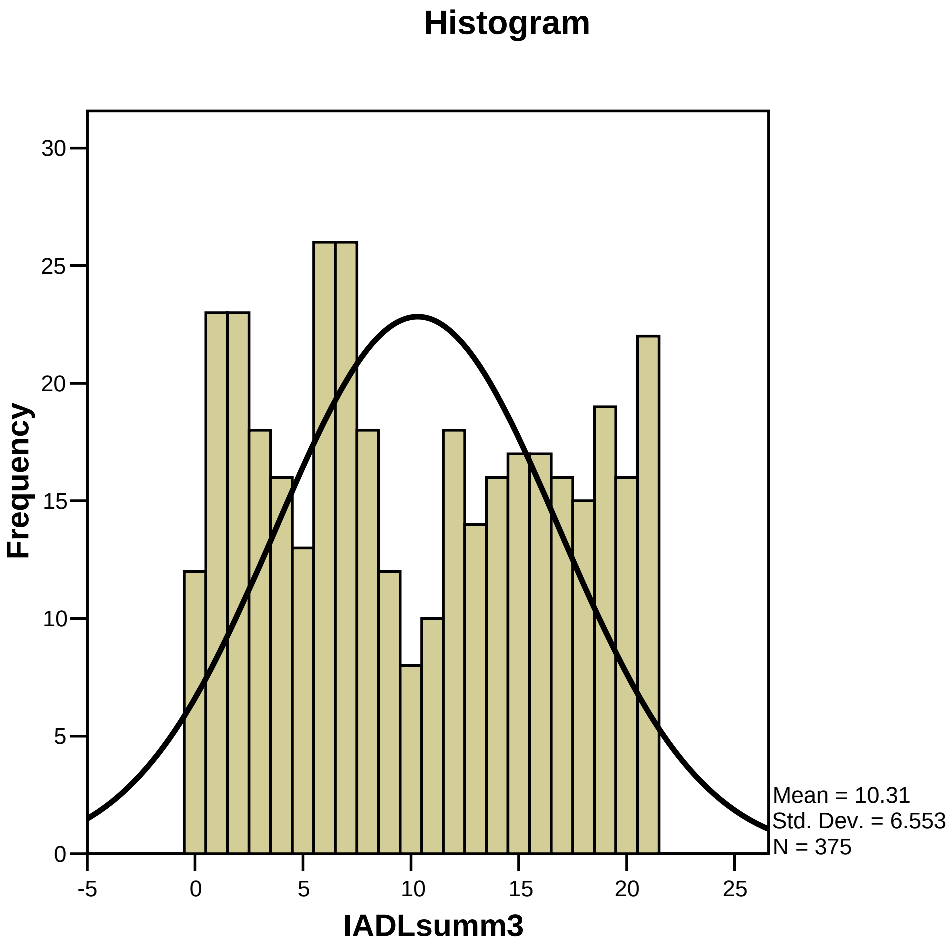
Table A.5.12: SPSS formulae to calculate severe impairment

0=	(303 < 2 OR 303 > 3) & (307 < 3)
1=	(303 = 2 OR 303 = 3) & (307 < 3) OR (307 > 2) & (303 < 2 OR 303 > 3)
2=	(303 = 2 OR 303 = 3) & (307 > 2)

Table A.5.13: SPSS formulae to reach the CPS scores

CPS score	Variables included in the calculation
0	Cognitive (B2a 3.03) < 4 & impairment = 0
1	Cognitive < 4 & impairment = 1
2	Cognitive < 4 & ANY(impairment, 2,3)
3	Cognitive < 4 & ANY(impairment, 2,3) & severe impairment =1
4	Cognitive < 4 & ANY(impairment, 2,3) & severe impairment = 2
5	Cognitive = 4 & eating (H2g 7.07) < 6
6	Cognitive =4 & eating (H2g 7.07) > 5

CPS = Cognitive performance scale



IADL = Instrumental activities of daily living

Figure A.5.1: Scree plot of IADL at 12 months

Table A.5.14: Calculation of ADL Self-performance hierarchy scale in SPSS

Score	Calculation of the variables
0	Locomotion = 0 & eating = 0 & toilet = 0& hygiene = 0
1	Locomotion = 1& eating ≤ 1 & toilet ≤ 1 & hygiene ≤ 1 OR Eating = 1 & locomotion ≤ 1 & hygiene ≤ 1 & toilet ≤ 1 OR Hygiene = 1 & locomotion ≤ 1 & eating ≤ 1 & toilet ≤ 1 OR Toilet = 1 & locomotion ≤ 1 & hygiene ≤ 1 & eating ≤ 1
2	Locomotion = 2 & eating ≤ 2 & toilet ≤ 2 & hygiene ≤ 2 OR Eating = 2 & locomotion ≤ 2 & hygiene ≤ 2 & toilet ≤ 2 OR Hygiene = 2 & locomotion ≤ 2 & eating ≤ 2 & toilet ≤ 2 OR Toilet = 2 & locomotion ≤ 2 & hygiene ≤ 2 & eating ≤ 2
3	Locomotion < 3 & eating < 3 & toilet ≥ 3 & hygiene ≥ 3
4	Locomotion = 3 OR eating = 3
5	Locomotion = 4 OR eating = 4
6	Locomotion = 4 & eating = 4 & toilet = 4 & hygiene = 4

ADL = Activities of daily living

Table A.5.15: CHESS formulae in SPSS

CHESS Scoring	Variables and scores used for the calculation
Base score	Add 6 items (Table 7.14) together then recode into a 0-2 scale (0 for no symptoms present, 1 for at least one symptom present and 2 for 2 or more symptoms present).
Second part	Decline in health = 1 + decline in cognition = 1 + decline in ADL = 1
Final total	Add the Base **score** to the second part to form the final score.

CHESS = Changes in health, end-stage disease and signs and symptoms

Table A.5.16: Pain formulae in SPSS

Score	Variables and scores used in the calculation
0	917recoded = 0
1	917 recoded = 1
2	ANY (917 recoded,2,3) & ANY (917 recoded, 1,2)
3	ANY (pain,2,3) & ANY (pain,3,4)

Table A.5.17: Items within the Caregivers reaction assessment scale

Items
Impact on schedule
1 Caregiver stopped work to care for the older person
2 Eliminated things from my schedule
3 My activities are centred around care
4 I visit family and friends less
5 I have many interruptions
Caregiver's self esteem
1 I feel privileged to care for the older person ^{R}
2 I want to care for them ^{R}
3 I enjoy caring for them ^{R}
4 Caring makes me feel good ^{R}
5 Caring is important to me ^{R}
6 I can never do enough to repay them ^{R}
7 I resent having to care for them
Family support
1 It is difficult for me to get help
2 I feel abandoned by my family
3 The family have left me alone
4 The family works to assist me ^{R}
5 Others have dumped the care on me
Health impact
1 I have enough physical strength to care for the older person ^{R}
2 I am healthy enough to care for the older person ^{R}
3 My health has become worse
4 I am tired all the time
Financial impact
1 It is difficult for me to pay for all the health needs
2 My finances are adequate ^{R}
3 There is a financial strain on the family

R = reversed scoring

Table A.5.18: SPSS calculations for stress levels by interview

Category of stress	Formulae
1	Assessment = 0 & Identify = 2 & CRATotind ≤ 10
2	Assessment = 0 & Identify = 2 & CRATotind > 10
3	Assessment = 0 & Identify = 2 & CRATotind > 11
4	Assessment = 0 & Identify = 2 & CRATotind > 12
5	Assessment = 0 & Identify = 2 & CRATotind > 13
6	Assessment = 0 & Identify = 2 & CRATotind > 14
7	Assessment = 0 & Identify = 2 & CRATotind > 15
8	Assessment = 0 & Identify = 2 & CRATotind > 16

Table A.5.19: Caregiver stress levels at each interview, with the older person in residential care or at home.

All caregivers	T_0	T_1	T_2	T_3	T_4
N	273	246	210	158	60
Mean	74.59	73.24	73.57	73.70	74.52
SD	9.07	9.15	8.71	9.38	8.46
Median	75.00	73.50	73.00	72.00	74.00
Range 0-120					
Caregivers of those older people living in residential care					
N	65	64	52	39	12
Mean	76.12	73.77	74.06	71.41	71.08
SD	10.03	9.24	9.24	9.82	7.03
Median	76.00	74.00	73.00	71.00	72.00
Range 0-120					
Caregivers of those older people living at home					
N	208	182	158	119	48
Mean	74.11	73.05	73.41	74.45	75.38
SD	8.72	9.13	8.55	9.15	8.64
Median	74.00	73.00	73.00	73.00	77.00
Range 0-120					

T= interview, 0= initial, 1= 3 month, 2= 6 month, 3= 12 month, 4-=18 month, SD = Standard deviation

Table A.5.20: Scoring changes from the ASPIRE questionnaire

Description of variable	Having no siblings/ child/family	Same house	1-5 miles	6-15 miles	16-50 miles	50+ miles
Questionnaire	a	b	c	d	e	f
New scoring	6	1	2	3	4	5
Variable name	Siblings far away					
	Child far away					
	Family far away					
Description of variable	No contact with relatives/ Friends/ neighbours	Daily	2-3 times a week	At least weekly	At least monthly	Less often
Questionnaire	a	b	c	d	e	f
New scoring	6	1	2	3	4	5
Variable name	Not seeing relatives					
	Not seeing friends					
	Not seeing neighbours					

Table A.5.21: Mean scores of older people at home and residential care (N=131)

Concerns about:	**Total**		**At home**		**In residential care**	
Housing	T_0	T_1	T_0	T_1	T_0	T_1
N	129	84	106	72	23	12
Mean	1.94	1.94	1.98	1.94	1.74	1.92
SD	0.24	0.24	0.14	0.23	0.45	0.29
Median	2.00	2.00	2.00	2.00	2.00	2.00
Range 1-4						
Coping						
N	131	85	106	73	25	12
Mean	2.82	1.95	2.97	1.96	2.20	1.92
SD	1.26	0.98	1.24	0.98	1.19	1.00
Median	3.00	2.00	4.00	2.00	2.00	1.50
Range 1-4						
Health						
N	131	85	106	73	25	12
Mean	1.92	2.33	1.95	2.33	1.80	2.33
SD	0.27	0.91	0.21	0.90	0.41	0.99
Median	2.00	3.00	2.00	3.00	2.00	3.00
Range 1-4						
Community support						
N	131	85	106	73	25	12
Mean	1.92	2.68	1.95	2.74	1.76	2.33
SD	0.28	0.70	0.21	0.62	0.44	0.99
Median	2.00	3.00	2.00	3.00	2.00	3.00
Range 1-4						

Concerns about:	**Total**		**At home**		**In residential care**	
Family support	T_0	T_1	T_0	T_1	T_0	T_1
N	131	85	106	73	25	12
Mean	1.94	1.86	1.97	1.85	1.80	1.92
SD	0.24	0.35	0.17	0.36	0.41	0.29
Median	2.00	2.00	2.00	2.00	2.00	2.00
Range 1-4						
Family doing too much						
N	131	40	106	27	25	13
Mean	3.56	2.17	3.69	2.19	2.98	2.15
SD	1.20	0.81	1.12	0.82	1.38	0.80
Median	3.50	2.00	4.00	2.00	3.00	2.00
Range 1-5						
Lonely						
N	131	85	106	73	25	12
Mean	3.54	1.91	3.58	1.89	3.40	2.00
SD	0.90	0.29	0.87	0.32	1.00	0.00
Median	4.00	2.00	4.00	2.00	4.00	2.00
Range 1-4						

T= interview, 0 = initial, 1 = 6 month, SD = Standard deviation. Ranges changed to account for smaller numbers in each category.

Table A.5.22: Health status of older people at each interview (N=569)

Cognitive performance scale	T_0	T_1	T_2	T_3	T_4
N	566	502	467	375	158
Mean	1.35	1.37	1.39	1.55	1.56
SD	1.21	1.40	1.39	1.41	1.52
Median	1.00	1.00	1.00	1.00	1.00
Range 0-6					
Depression scale					
N	566	502	467	375	158
Mean	3.09	2.58	2.43	2.08	1.93
SD	2.71	2.45	2.40	2.03	2.13
Median	2.00	2.00	2.00	2.00	1.00
Range 0-14					
Instrumental activities of daily living					
N	566	502	467	375	158
Mean	10.24	10.49	10.55	10.31	10.28
SD	5.80	6.23	6.53	6.55	6.84
Median	10.00	10.00	10.00	10.00	9.00
Range 0-21					
Activities of daily living					
N	566	502	467	375	158
Mean	0.46	0.46	0.52	0.55	0.66
SD	1.12	1.14	1.20	1.20	1.47
Median	0.00	0.00	0.00	0.00	0.00
Range 0-6					
Changes in health end-stage disease, signs and symptoms					
N	566	502	nil	375	158
Mean	2.43	2.21		2.06	1.97
SD	1.14	1.12		1.11	1.10
Median	2.00	2.00		2.00	2.00
Range 0-5					

T= interview, 0= initial, 1= 3 month, 2= 6 month, 3= 12 month, 4-=18 month, SD = Standard deviation

Pain scale	**T_0**	**T_1**	**T_2**	**T_3**	**T_4**
N	566	502	467	375	158
Mean	1.23	1.17	1.23	1.11	1.17
SD	1.21	1.23	1.16	1.10	1.08
Median	1.00	1.00	1.00	1.00	1.00
Range 0-3					
Prior hospitalisation					
N	566	502	nil	375	158
Mean	0.52	0.52		0.50	0.42
SD	0.50	0.50		0.50	0.50
Median	1.00	1.00		0.00	0.00
Range 0-1					
Lonely					
N	565	502	nil	375	158
Mean	0.26	0.26		0.24	0.25
SD	0.44	0.44		0.43	0.43
Median	0.00	0.00		0.00	0.00
Range 0-1					
Family far away					
N	565	502		375	158
Mean	2.12	1.35		1.26	1.22
SD	1.09	0.59		0.49	0.45
Median	2.00	1.00		1.00	1.00
Range 0-5					
Not being home alone					
N	566	502		375	158
Mean	1.57	1.47		1.40	1.47
SD	1.12	1.17		1.26	1.30
Median	2.00	2.00		1.00	1.50
Range 0-3					

Child far away	T_0	T_1	T_2	T_3	T_4
N	565	502	nil	375	158
Mean	2.12	1.84		2.21	2.11
SD	1.33	1.24		1.27	1.24
Median	2.00	1.00		2.00	2.00
Range 0-5					
Sibling far away					
N	566	502		375	158
Mean	2.55	2.45		2.51	2.32
SD	2.14	1.96		2.12	2.08
Median	2.00	2.00		2.00	2.00
Range 0-5					
Family far away					
N	565	502		375	158
Mean	2.30	2.75		2.39	2.32
SD	1.46	1.63		1.36	1.21
Median	2.00	3.00		2.00	2.00
Range 0-5					
Not seeing friends					
N	565	502		375	158
Mean	2.38	2.24		2.62	2.73
SD	1.58	1.53		1.54	1.66
Median	2.00	2.00		3.00	3.00
Range 0-5					
Not seeing neighbours					
N	565	502		375	158
Mean	2.12	1.91		2.23	2.16
SD	1.68	1.61		1.72	1.79
Median	2.00	2.00		2.00	2.00
Range 0-5					

T= interview, 0= initial, 1= 3 month, 3= 12 month, 4-=18 month, SD = Standard deviation

Table A.5.23: Health status for older people living at home

Cognitive performance scale	T_0	T_1	T_2	T_3	T_4
N	465	403	380	303	133
Mean	1.27	1.21	1.22	1.34	1.35
SD	1.20	1.33	1.34	1.33	1.41
Median	1.00	1.00	1.00	1.00	1.00
Range 0-6					
Depression scale					
N	465	403	380	303	133
Mean	2.97	2.43	2.24	1.97	1.76
SD	2.66	2.28	2.25	1.92	1.99
Median	2.00	2.00	2.00	1.00	1.00
Range0-14					
Instrumental activities of daily living					
N	465	4.3	380	303	133
Mean	9.64	9.24	9.21	8.64	8.90
SD	5.83	5.92	6.17	6.02	6.39
Median	9.00	8.00	8.00	7.00	7.00
Range 0-21					
Activities of daily living					
N	465	403	380	303	133
Mean	0.41	0.29	0.34	0.29	0.39
SD	1.09	0.95	0.97	0.92	1.15
Median	0.00	0.00	0.00	0.00	0.00
Range 0-6					
Changes in health end-stage disease, signs and symptoms					
N	465	403	nil	303	133
Mean	2.38	2.08		1.97	1.90
SD	1.12	1.07		1.11	1.09
Median	2.00	2.00		2.00	2.00
Range 0-5					

Pain scale	**T_0**	**T_1**	**T_2**	**T_3**	**T_4**
N	465	403	380	303	133
Mean	1.23	1.18	1.29	1.18	1.20
SD	1.20	1.22	1.16	1.10	1.07
Median	1.00	1.00	1.00	1.00	1.00
Range 0-3					
Prior hospitalisation					
N	465	403	nil	303	133
Mean	0.53	0.50		0.48	0.41
SD	0.50	0.50		0.50	0.49
Median	1.00	1.00		0.00	0.00
Range 0-1					
Lonely					
N	465	403	nil	303	133
Mean	0.25	0.25		0.25	0.24
SD	0.44	0.43		0.43	0.43
Median	0.00	0.00		0.00	0.00
Range 0-1					
Family far away					
N	465	403	nil	303	133
Mean	2.07	1.32		1.23	1.19
SD	1.04	0.56		0.47	0.43
Median	2.00	1.00		1.00	1.00
Range 0-5					
Not being home alone					
N	566	502	nil	375	158
Mean	1.57	1.47		1.40	1.47
SD	1.12	1.17		1.26	1.30
Median	2.00	2.00		1.00	1.50
Range 0-3					

Child far away	T_0	T_1	T_2	T_3	T_4
N	465	403	nil	303	133
Mean	2.11	1.78		2.09	1.97
SD	1.32	1.22		1.26	1.24
Median	2.00	1.00		2.00	2.00
Range 0-5					
Sibling far away					
N	465	403	nil	303	133
Mean	2.57	2.49		2.58	2.30
SD	2.12	1.92		2.09	2.07
Median	2.00	2.00		2.00	2.00
Range 0-5					
Family far away					
N	465	403	nil	303	133
Mean	2.34	2.76		2.34	2.30
SD	1.48	1.66		1.35	1.24
Median	2.00	3.00		2.00	2.00
Range 0-5					
Not seeing friends					
N	465	403	nil	303	133
Mean	2.37	2.27		2.54	2.77
SD	1.55	1.50		1.50	1.59
Median	2.00	2.00		3.00	3.00
Range 0-5					
Not seeing neighbours					
N	465	403	nil	303	133
Mean	2.12	2.00		2.42	2.38
SD	1.68	1.61		1.70	1.84
Median	2.00	2.00		2.00	2.00
Range 0-5					

T= interview, 0= initial, 1= 3 month, 3= 12 month, 4-=18 month, SD = Standard deviation

Table A.5.24: Health status for older people living in residential care

Cognitive performance scale	**T_0**	**T_1**	**T_2**	**T_3**	**T_4**
N	101	99	87	72	25
Mean	1.72	2.05	2.14	2.44	2.72
SD	1.23	1.50	1.37	1.41	1.54
Median	2.00	2.00	2.00	3.00	2.00
Range 0-6					
Depression scale					
N	101	99	87	72	25
Mean	3.63	3.19	3.25	2.56	2.84
SD	2.90	3.02	2.83	2.41	2.61
Median	3.00	2.00	3.00	2.00	2.00
Range0-14					
Instrumental activities of daily living					
N	101	99	87	72	25
Mean	12.99	15.56	16.40	19.35	17.60
SD	4.84	4.74	4.57	3.16	3.89
Median	14.00	17.00	18.00	18.00	18.00
Range 0-21					
Activities of daily living					
N	101	99	87	72	25
Mean	0.68	1.13	1.33	1.61	2.08
SD	1.24	1.56	1.68	1.96	2.08
Median	0.00	0.00	1.00	1.00	2.00
Range 0-6					
Changes in health end-stage disease, signs and symptoms					
N	101	99	nil	72	25
Mean	2.64	2.67		2.40	2.36
SD	1.19	1.20		1.07	1.11
Median	3.00	3.00		2.00	3.00
Range 0-5					

Pain scale	**T_0**	**T_1**	**T_2**	**T_3**	**T_4**
N	100	99	87	72	25
Mean	1.22	1.11	0.97	0.83	1.04
SD	1.20	1.20	1.14	1.04	1.14
Median	1.00	1.00	0.00	0.00	1.00
Range 0-3					
Prior hospitalisation					
N	100	99	nil	72	25
Mean	0.46	0.59		0.58	0.48
SD	0.50	0.50		0.50	0.51
Median	0.00	1.00		1.00	0.00
Range 0-1					
Lonely					
N	100	99	nil	72	25
Mean	0.29	0.33		0.21	0.28
SD	0.46	0.47		0.41	0.46
Median	0.00	0.00		0.00	0.00
Range 0-1					
Family far away					
N	100	99	nil	72	25
Mean	2.36	1.47		1.38	1.40
SD	1.25	0.68		0.57	0.50
Median	2.00	1.00		1.00	1.00
Range 0-5					
Not being home alone					
N	100	99	nil	72	25
Mean	1.49	1.09		0.35	0.24
SD	1.09	1.10		0.61	0.52
Median	2.00	1.00		0.00	0.00
Range 0-3					

Child far away	T_0	T_1	T_2	T_3	T_4
N	100	99	nil	72	25
Mean	2.14	2.08		2.69	2.84
SD	1.36	1.27		1.18	0.99
Median	2.00	2.00		2.00	3.00
Range 0-5					
Sibling far away					
N	100	99	nil	72	25
Mean	2.45	2.31		2.22	2.40
SD	2.21	2.12		2.26	2.18
Median	2.00	2.00		2.00	3.00
Range 0-5					
Family far away					
N	100	99	nil	72	25
Mean	2.12	2.70		2.61	2.44
SD	1.39	1.51		1.37	1.00
Median	2.00	3.00		2.00	2.00
Range 0-5					
Not seeing friends					
N	100	99	nil	72	25
Mean	2.41	2.09		2.96	2.56
SD	1.72	1.67		1.66	2.02
Median	2.00	2.00		3.00	3.00
Range 0-5					
Not seeing neighbours					
N	100	99	nil	72	25
Mean	2.11	1.57		1.40	1.00
SD	1.71	1.56		1.54	0.91
Median	2.00	1.00		1.00	1.00
Range 0-5					

T= interview, 0= initial, 1= 3 month, 3= 12 month, 4-=18 month, SD = Standard deviation

Table A.5.25: ASPIRE older people’s questionnaire

Older Person	**ASPIRE**	
No	**Question**	**Answer**
Section 1	**Vital status/** **Assessment Details**	
Registration Number		
Date of Birth	D D M M Y Y Y Y	
Initials		
1.01	Assessment date	
1.02	Have you completed a Form Z	0. No 1. Yes
1.03	Assessment	
1.04	Participant is alive on scheduled assessment date	0. No 1. Yes 2. Unknown
1.05	If unknown, Date last definitely known to be alive	D D M M Y Y Y Y
1.06	If No, Date of Death	D D M M Y Y
1.07	Is further data being obtained for this scheduled assessment	0. No 1. Yes
1.08	If No, reason for *missed* assessment	
1.09	Data Collection Type	a. Face to Face b. Phone
Section 2	**General Questions**	
First, I am going to ask you some general questions		

2.01	What is your usual place of residence	0. Own home 1. Family members home 2. Retirement unit/ village 3. Community residential home 4. Rest home 5. Private hospital
2.02	Are you currently living at your usual permanent address	0= No, 1=Yes If no, complete Form Z
2.03	What is your main caregiver's relationship to you	1. Spouse 2. Sibling 3. Child 4. Other relative 5. Neighbour 6. Other
2.04	What is your marital status	0. Married/ Defacto 1. Widowed 2. Never married 3. Separated/ divorced
2.05	What is the highest level of education that you attained	0. Primary School 1. High School 2. Polytechnic 3. University
2.06	What is or was your main occupation	
Code (office use)		
2.07	What is or was your spouse's occupation	
Code (office use)		
2.08	Have you had any admissions to hospital in the last 12 months	0=No, 1=Yes

2.09	If yes, What was you length of stay (days) for your most recent admissions in past 12 months	Admission 1 | 2 | 3 | 4
2.10	In the last month, how many times have you visited your GP	0. 0 1. 1 2. 2 3. 3 or more
2.11	In the last month, how many times has your GP visited you at home	0. 0 1. 1 2. 2 3. 3 or more
2.12	How much do you pay on average when you visit your GP	$
2.13	Do you hold a community services card	0=no, 1=yes
2.14	Have you resided in a rest home/ residential care/ private hospital facility in the past five years	0=no, 1=yes
Section 3	**Memory/ Hearing/ Communication/ Vision**	
3.01	Procedural memory	0=Memory OK, 1=Memory problem
What were those 3 items I asked you to remember		
3.02	Short Term Memory	0. Able to remember 3 items 1. Unable to remember 3 items
3.03	How well older person makes decisions about organising the day	0. Independent 1. Modified Independence 2. Minimally Impaired 3. Moderately Impaired

		4. Severely Impaired
3.04	Has there been a decline in your abilities to make decisions in the last 3 months?	0=No, 1=Yes
3.05	Has there been any change in your memory or thinking in the last 7 days?	0. No 1. Yes
The next questions relate to your hearing, communication and vision		
3.06	Do you have any problems with your hearing?	0. Hears Adequately without hearing aid 1. Hears Adequately with hearing aid 2. Minimal Difficulty 3. Hears with some difficulty 4. Highly Impaired
3.07	Making Self Understood (language expression)	0. Understood 1. Difficulty with occasional word/ thoughts 2. Some difficulty with expression 3. Moderate difficulty with expression 4. Severe difficulty with expression
3.08	Ability to Understand language	0. Clear Comprehension 1. Usually Understands 2. Often Understands 3. Sometimes Understands 4. Rarely/Never Understands
3.09	Has there been a decline in your communication in the last 3 months	0. No 1. Yes
3.10	Do you have any problems with your	0. No 1. Yes

	vision	
3.11	Vision	2. Adequate 3. Impaired 4. Moderately impaired 5. Highly impaired 6. Severely impaired
3.12	Visual Limitation/Difficulties	0. No 1. Yes
3.13	Has your vision worsened in the last 3 months	0. No 1. Yes
Section 4	**Mood/ Emotions**	
4.01	In the last 3 days, have you felt sad, depressed or low in spirits	0. No 1. Some of the time 2. All of the time
4.02	In the last 3 days, have you felt angry with yourself or others	0. No 1. Some of the time 2. All of the time
4.03	In the last 3 days, have you been fearful of anything	0. No 1. Some of the time 2. All of the time
4.04	In the last 3 days, have you been worrying about your health	0. No 1. Some of the time 2. All of the time days
4.05	In the last 3 days, been feeling anxious	0. No 1. Some of the time 2. All of the time
4.06	In the last 3 days, have you been sad or worried	0. No 1. Some of the time 2. All of the time

4.07	In the last 3 days, have you had episodes of crying, tearfulness	0. No 1. Some of the time 2. All of the time
4.08	In the last 3 days, have you lost interest in your activities	0. No 1. Some of the time 2. All of the time
4.09	In the last 3 days, have you withdrawn from your family or friends	0. No 1. Some of the time 2. All of the time
4.10	In the last 3 days, have you had any disturbance in your sleep	0. No 1. Some of the time 2. All of the time
4.11	Has there been any disturbance of your mood in the last 3 months	0=No, 1=Yes
Section 5	**Relationships/ Informal Support Services**	
5.01	Do you have visitors and/or do you go and visit other people? Do you enjoy their company?	0. At ease 1. Not at ease
5.02	Are there any current problems or difficulties with others	0. No conflict 1. Conflict/ stress with others
5.03	Has there been any reduction in the level of your social activities in the last 3 months	0. No decline 1. Decline and distressed 2. Decline, but not distressed
5.04	In a typical day, how much are you on your own	0. Never or hardly ever 1. About one hour 2. Long periods of time (e.g. All morning)

		3. All of the time
5.05	Do you feel lonely when you are alone	0. No 1. Yes
I now want to ask you about the people who help you		
Informal Support Services		
5.06	How far away does your nearest relative live? (Do not include spouse)	a. No relatives b. Same house/ within one mile c. 1-5 miles (1.5-8.0 km) d. 6-15 miles (9-24 km) e. 16-50 miles (25-80 km) f. 50+ miles (81+ km)
5.07	If you have any children, where does your nearest child live?	a. No children b. Same house/ within one mile c. 1-5 miles (1.5-8.0 km) d. 6-15 miles (9-24 km) e. 16-50 miles (25-80 km) f. 50+ miles (81+ km)
5.08	If you have any living sisters or brothers, where does your nearest sister or brother live?	a. No siblings b. Same house/ within one mile c. 1-5 miles (1.5-8.0 km) d. 6-15 miles (9-24 km) e. 16-50 miles (25-80 km) f. 50+ miles (81+ km)
5.09	How often do you see any of your relatives to speak to?	a. Never/ no relatives b. Daily c. 2-3 times a week d. At least weekly e. At least monthly f. Less often

5.10	If you have friends in this community/ neighbourhood, how often do you have a chat or do something with one of your friends?	a. Never/ no friends b. Daily c. 2-3 times a week d. At least weekly e. At least monthly f. Less often
5.11	How often do you see any of your neighbours to have a chat with or do something with?	a. No contact with neighbours b. Daily c. 2-3 times a week d. At least weekly e. At least monthly f. Less often
5.12	Do you attend any religious meetings?	a. Yes, regularly b. Yes, occasionally c. No
5.13	Do you attend meetings of any community/ neighbourhood or social groups, such as old people's clubs, lectures or anything like that	a. Yes, regularly b. Yes, occasionally c. No
Section 6	**Household Activities**	
6.01	Preparing meals	0. Independent 1. Some help 2. Full help 3. By others 8. Activity did not occur
6.02	Is this difficult for you to do	0. No difficulty 1. Some difficulty 2. Great difficulty
6.03	Ordinary Housework	0. Independent 1. Some help 2. Full help

		3. By others 8. Activity did not occur
6.04	Is this difficult for you to do (if you did it)	0. No difficulty 1. Some difficulty 2. Great difficulty
6.05	Managing your Finances	0. Independent 1. Some help 2. Full help 3. By others 8. Activity did not occur
6.06	Is this difficult for you to do (if you did it)	0. No difficulty 1. Some difficulty 2. Great difficulty
6.07	Managing your medications	0. Independent 1. Some help 2. Full help 3. By others 8. Activity did not occur
6.08	Is this difficult for you to do (if you did it)	0. No difficulty 1. Some difficulty 2. Great difficulty
6.09	Using the telephone	0. Independent 1. Some help 2. Full help 3. By others 8. Activity did not occur
6.10	Is this difficult for you to do (if you did it)	0. No difficulty 1. Some difficulty 2. Great difficulty

6.11	Shopping for food and household items	0. Independent 1. Some help 2. Full help 3. By others 8. Activity did not occur
6.12	Is this difficult for you to do (if you did it)	0. No difficulty 1. Some difficulty 2. Great difficulty
6.13	Travelling outside the house	0. Independent 1. Some help 2. Full help 3. By others 8. Activity did not occur
6.14	Is this difficult for you to do (if you did it)	0. No difficulty 1. Some difficulty 2. Great difficulty
6.15	Who mainly provides the help with transportation if you need it	0. No one – independent 1. Spouse 2. Family member 3. Friend 4. Neighbour 5. Volunteer 6. Home care support 7. Taxi
6.16	Who mainly pays for the running costs or fare for your transportation	0. Self-paid 1. Person providing the transport 2. Caregiver or family who does not provide transport 3. Volunteer organisation 4. Vouchers provided by social organisations
6.17	If you needed help, how many trips in a car or van did you have in	____________

	past 7 days with assistance	
6.18	When you received help, what is the average length of time in a car or van for a trip during the last 7 days	___________ mins
Section 7	**Personal Care**	
7.01	Mobility in Bed	0. Independent 1. Setup help only 2. Supervision 3. Limited assistance 4. Extensive Assistance 5. Maximal Assistance 6. Total Dependence 8. Activity did not occur
7.02	Transferring from a bed or chair	0. Independent 1. Setup help only 2. Supervision 3. Limited assistance 4. Extensive Assistance 5. Maximal Assistance 6. Total Dependence 8. Activity did not occur
7.03	Walking about the home	0. Independent 1. Setup help only 2. Supervision 3. Limited assistance 4. Extensive Assistance 5. Maximal Assistance 6. Total Dependence 8. Activity did not occur

7.04	Walking outside the house	0. Independent 1. Setup help only 2. Supervision 3. Limited assistance 4. Extensive Assistance 5. Maximal Assistance 6. Total Dependence 8. Activity did not occur
7.05	Dressing your upper body	0. Independent 1. Setup help only 2. Supervision 3. Limited assistance 4. Extensive Assistance 5. Maximal Assistance 6. Total Dependence 8. Activity did not occur
7.06	Dressing your lower body	0. Independent 1. Setup help only 2. Supervision 3. Limited assistance 4. Extensive Assistance 5. Maximal Assistance 6. Total Dependence 8. Activity did not occur
7.07	Eating meals	0. Independent 1. Setup help only 2. Supervision 3. Limited assistance 4. Extensive Assistance 5. Maximal Assistance 6. Total Dependence 8. Activity did not occur

7.08	Going to the toilet.	0. Independent 1. Setup help only 2. Supervision 3. Limited assistance 4. Extensive Assistance 5. Maximal Assistance 6. Total Dependence 8. Activity did not occur
7.09	Washing your face, brushing your teeth etc.	0. Independent 1. Setup help only 2. Supervision 3. Limited assistance 4. Extensive Assistance 5. Maximal Assistance 6. Total Dependence 8. Activity did not occur
7.10	Bathing/ showering	0. Independent 1. Setup help only 2. Supervision 3. Limited assistance 4. Extensive Assistance 5. Maximal Assistance 6. Total Dependence 8. Activity did not occur
7.11	Have you needed any help with these things in the last 3 months?	0. No 1. Yes
7.12	Do you use any aids or devices for your mobility inside the home	0. No 1. Yes 2. Activity did not occur
7.13		

Walking stick	0. No 1. Yes
Zimmer frame	0. No 1. Yes
Scooter (motorised cart, NOT electric wheelchair)	0. No 1. Yes
Wheelchair	0. No 1. Yes

7.14	Do you use any aids or devices for your mobility outside the home	0. No 1. Yes 2. Activity did not occur

7.15	
Walking stick	0. No 1. Yes
Zimmer frame	0. No 1. Yes
Scooter	0. No 1. Yes
Wheelchair	0. No 1. Yes

7.16	Are you able to manage climbing stairs	2. Up and down stairs without help (can use handrail) 3. Up and down stairs with help 4. Not gone up and down stairs-but could without help 5. Not gone up and down stairs-but could with help 6. Not gone up and down stairs-no capacity to do it 8. Unknown-did not climb stairs, assessor is unable to judge whether capacity exists

Now I am going to ask you some questions about your energy levels

7.17	How often have you gone outside of the house in the last month	0. Every day 1. 2-6 days a week 2. 1 day a week 3. No days
7.18	In the last 3 days, how much activity/ exercise have you done where you are continually on the go or moving about	0. Two or more hours 1. Less than 2 hours
I am now going to ask about your bladder and bowel function over the last week		
7.19	Have you lost control of your bladder? Had any accidents with your urine?	0. Continent 1. Continent with catheter 2. Usually Continent 3. Occasionally Incontinent 4. Frequently Incontinent 5. Incontinent 8. Did not occur
7.20	Has this changed in the last 3 months	0. No 1. Yes
7.21	Do you use any pads or devices?	0. No 1. Yes
7.22		
Use of pads or briefs to protect against wetness		0. No 1. Yes
Use of indwelling catheter		0. No 1. Yes
7.23	Have you had any accidents with your bowels in the last 7 days	2. Continent 3. Continent with ostomy 4. Usually continent 5. Occasionally incontinent 6. Frequently incontinent

		7. Incontinent 8. Did not occur
Section 8	**Medical Conditions**	
8.01	Cerebrovascular accident (stroke)	0. Not present 1. Present
8.02	Heart failure	0. Not present 1. Present
8.03	Coronary artery disease, angina (Heart attack)	0. Not present 1. Present
8.04	Hypertension, high blood pressure	0. Not present 1. Present
8.05	Irregular pulse (arrhythmia), fibrillation	0. Not present 1. Present
8.06	Peripheral vascular disease, pain in legs when walking	0. Not present 1. Present
8.07	Alzheimer's disease	0. Not present 1. Present
8.08	Dementia other than Alzheimer's disease	0. Not present 1. Present
8.09	Head injury	0. Not present 1. Present
8.10	Paralysis in the arm or leg	0. Not present 1. Present
8.11	Multiple sclerosis	0. Not present 1. Present
8.12	Parkinson's disease	0. Not present

		1. Present
8.13	Arthritis in the joints	0. Not present 1. Present
8.14	Hip fracture	0. Not present 1. Present
8.15	Other fractures (e.g. Wrist, vertebral)	0. Not present 1. Present
8.16	Osteoporosis, thinning of the bones	0. Not present 1. Present
8.17	Cataracts	0. Not present 1. Present
8.18	Glaucoma	0. Not present 1. Present
8.19	Any psychiatric illness (such as depression)	0. Not present 1. Present
8.20	HIV Infection	0. Not present 1. Present
8.21	Pneumonia	0. Not present 1. Present
8.22	Tuberculosis, TB	0. Not present 1. Present
8.23	Urinary Tract Infection in the last month	0. Not present 1. Present
8.24	Cancer in last 5 years not including Skin Cancer	0. Not present 1. Present
8.25	Diabetes	0. Not present 1. Present
8.26	Emphysema/COPD/Asthma	0. Not present 1. Present
8.27	Kidney failure	0. Not present

		1. Present
8.28	Thyroid disease (hyper or hypo, nodules)	0. Not present 1. Present
8.29	Any other important medical problem	0. Not present 1. Present
8.30		If yes, please name _____________
Spec_1		
Spec_2		
Spec_3		
Section 9		**Recent Health**
In the last 2 years, have you had any of the following:		
9.01	Your Blood pressure measured	0. No 1. Yes
9.02	Received an influenza (flu) vaccination	0. No 1. Yes
9.03	Been Tested for blood in stool or screening endoscopy (camera inserted into the bowel or down the throat)	0. No 1. Yes
9.04	IF FEMALE: Received breast examination or mammography	0. No 1. Yes
9.05	IF MALE: Received prostate examination	0. No 1. Yes
In the last 3 days have you had any of the following:		
9.06	Diarrhoea	0. No 1. Yes
9.07	Difficulty urinating or urinating 3 or more times at	0. No 1. Yes

	night	
9.08	Fever (temperatures above 38°C recorded on more than one occasion)	0. No 1. Yes
9.09	Loss of appetite	0. No 1. Yes
9.10	Vomiting	0. No 1. Yes
9.11	Chest pain/pressure at rest or exertion	0. No 1. Yes
9.12	No bowel movements in 3 days	0. No 1. Yes
9.13	Dizziness or light headedness	0. No 1. Yes
9.14	Oedema	0. No 1. Yes
9.15	Shortness of Breath	0. No 1. Yes
9.16	Do you suffer from any pain	0. No 1. Yes
9.17	Frequency of pain	0. Less than daily 1. Daily-one period 2. Daily-multiple periods (e.g. Morning & evening)
9.18	Intensity	0. Mild 1. Moderate 2. Severe 3. Times when pain is horrible or excruciating
9.19	Does the pain interfere with your activities	0. No 1. Yes

9.20	Where is the pain located	0. Localised – single site 1. Multiple sites
9.21	How well does medications control the pain	0. Medicine controls pain 1. Medications do not adequately control pain 2. Pain present, medication not taken
9.22	Have you had a fall in the last 3 months?	0. No 1. Yes
9.23	How many falls have you had in the last 3 months	1, 2, 3, 4, 5, 6, 7, 8, 9
9.24	Please walk across the room (Interviewer to grade gait)	0. Stable gait 1. Unstable gait
9.25	Are you frightened of having a fall	0. No 1. Yes
9.26	Does this limit your activities	0. No 1. Yes
9.27	Do you drink alcohol?	0. No 1. Yes
9.28	Have you been told or felt the need to reduce the amount of alcohol you drink	0. No 1. Yes
9.29	Do you need a drink in the morning to steady your nerves	0. No 1. Yes
9.30	Do you smoke or chew tobacco	0. No 1. Yes
Section 10	**Status Indicators**	
Health Status Indicators		

10.01	Older person feels he/she has poor health (when asked)	0. No 1. Yes
10.02	Has conditions or diseases that make cognition, ADL, mood or behavioural patterns unstable (fluctuating, precarious, deteriorating)	0. No 1. Yes
10.03	Experiencing a flare-up of a recurrent or chronic problem	0. No 1. Yes
10.04	Treatments changed in last 30 days because of a new acute episode or condition	0. No 1. Yes
10.05	Prognosis is Less than six months to live	0. No 1. Yes
Other Status Indicators		
10.06	Fearful of a family member or caregiver	0. No 1. Yes
10.07	Unusually poor hygiene	0. No 1. Yes
10.08	Unexplained injuries, broken bones, burns	0. No 1. Yes
10.09	Neglected, abused, or mistreated	0. No 1. Yes
10.10	Physically restrained	0. No 1. Yes
Section 11	**General Status**	
11.01	Have you lost any weight in the last month?	0. No 1. Yes

11.02	Are you concerned about the amount of weight you have lost in the last month	0. No 1. Yes
11.03	Interviewer to grade: Severe malnutrition (cachexia)	0. No 1. Yes
11.04	Interviewer to grade: Morbid Obesity	0. No 1. Yes
11.05	In last 3 days, have you eaten less than 2 meals a day	0. No 1. Yes
11.06	In last 3 days, has there been a noticeable decrease in the amount of food that you eat	0. No 1. Yes
11.07	Insufficient fluids consumed	0. No 1. Yes
11.08	Do you require any assisted tube feeding	0. No 1. Yes
11.09	Have you required any special foods because of problems with swallowing	0. Normal 1. Requires diet modification to swallow solid foods 2. Requires modification to swallow solid foods and liquids 3. Combined oral and tube feeding) 4. No oral intake
11.10	Have there been any problems with your teeth, dentures, saliva production or mouth	0. No 1. Yes
11.11		

Problem chewing or swallowing (e.g. Poor mastication, immobile jaw, surgical resection, decreased sensation/motor control, pain while eating)		0. No 1. Yes
Mouth is dry when eating a meal		0. No 1. Yes
Problem brushing teeth or dentures		0. No 1. Yes
11.12	Have you any problems with your skin	0. No 1. Yes
11.13	Do you have any ulcers?	0. No ulcer 1. Stage1-Ulcers include any area of persistent skin redness 2. Stage 2-Partial loss of skin layers 3. Stage 3-Deep craters in the skin 4. Stage 4- Breaks in skin exposing muscle or bone
11.14	Pressure Ulcer	0. No 1. Yes
11.15	Stasis Ulcer	0. No 1. Yes
11.16	Do you have any other skin problems requiring treatment	0. No 1. Yes
11.17		Burns (second or third degree)
Open lesions other than ulcers, rashes, cuts (e.g.: cancer)		0. No 1. Yes
Skin tears or cuts		0. No 1. Yes
Surgical wound		0. No 1. Yes

Corns, calluses, structural problems, infections, fungi		0. No 1. Yes
11.18	Have you had an ulcer on your body at any time	0. No 1. Yes
11.19	Have you received wound or ulcer care in the last 7 days. What sort of care.	0. No 1. Yes
11.20		
Antibiotic, systemic or topical		0. No 1. Yes
Dressings		0. No 1. Yes
Surgical wound care		0. No 1. Yes
Other wound/ulcer care		0. No 1. Yes
Section 12	**Home Environment**	
12.01	Lighting in evening	0. Safe 1. Problem
Why		
12.02	Flooring and carpeting	0. Safe 1. Problem
Why		
12.03	Bathroom and toilet room	0. Safe 1. Problem
Why		
12.04	Kitchen	0. Safe 1. Problem
Why		

12.05	Heating and cooling	0. Safe 1. Problem
Why		
12.06	Personal safety	0. Safe 1. Problem
Why		
12.07	Access to home	0. Safe 1. Problem
Why		
12.08	Access to rooms in house	0. Safe 1. Problem
Why		
12.09	In the last 3 months, have you had a change in the number of people living with you	0. No 1. Yes
12.10	Do you feel you would be better off living elsewhere	0. No 1. Yes
Section 13	**Community Services**	
in the last 4 weeks Have you received any of the following:		
13.01	Home carers	Days Hours Minutes
13.02	Who paid for this service	0. Personal payment 1. Caregiver 2. Insurance 3. Residential Home 4. DHB 5. ACC
13.03	Visiting nurses	Days Hours Minutes

13.04	Where did this take place	0. Professionals office/ practice 1. At home 2. Outpatient clinic 3. Hospital 4. Residential Home 5. Other
13.05	Who paid for this service	0. Personal payment 1. Caregiver 2. Insurance 3. Residential Home 4. DHB 5. ACC
13.06	Home help	Days Hours Minutes
13.07	Who paid for this service	0. Personal payment 1. Caregiver 2. Insurance 3. Residential Home 4. DHB 5. ACC
13.08	Number of Meals on wheels in past month	
13.09	Who paid for this service	0. Personal payment 1. Caregiver 2. Insurance 3. Residential Home 4. DHB 5. ACC
13.10	Volunteer services	Days Hours Minutes

13.11	Who paid for this service	0. Personal payment 1. Caregiver 2. Insurance 3. Residential Home 4. DHB 5. ACC
13.12	Physiotherapy	Days Hours Minutes
13.13	Where did this take place	0. Professionals office/ practice 1. At home 2. Outpatient clinic 3. Hospital 4. Residential Home 5. Other
13.14	Who paid for this service	0. Personal payment 1. Caregiver 2. Insurance 3. Residential Home 4. DHB 5. ACC
13.15	Occupational therapy	Days Hours Minutes
13.16	Where did this take place	0. Professionals office/ practice 1. At home 2. Outpatient clinic 3. Hospital 4. Residential Home 5. Other
13.17	Who paid for this service	0. Personal payment 1. Caregiver 2. Insurance 3. Residential Home

		4. DHB 5. ACC
13.18	Speech therapy	Days Hours Minutes
13.19	Where did this take place	0. Professionals office/ practice 1. At home 2. Outpatient clinic 3. Hospital 4. Residential Home 5. Other
13.20	Who paid for this service	0. Personal payment 1. Caregiver 2. Insurance 3. Residential Home 4. DHB 5. ACC
13.21	Day care or Day hospital	Days Hours Minutes
13.22	Who paid for this service	0. Personal payment 1. Caregiver 2. Insurance 3. Residential Home 4. DHB 5. ACC
13.23	Social worker	Days Hours Minutes
13.24	Where did this take place	0. Professionals office/ practice 1. At home 2. Outpatient clinic 3. Hospital 4. Residential Home 5. Other

13.25	Who paid for this service	0. Personal payment 1. Caregiver 2. Insurance 3. Residential Home 4. DHB 5. ACC
13.26	Dietician	Days Hours Minutes
13.27	Where did this take place	0. Professionals office/ practice 1. At home 2. Outpatient clinic 3. Hospital 4. Residential Home 5. Other
13.28	Who paid for this service	0. Personal payment 1. Caregiver 2. Insurance 3. Residential Home 4. DHB 5. ACC
13.29	Medical Specialist	Days Hours Minutes
13.30	Where did this take place	0. Professionals office/ practice 1. At home 2. Outpatient clinic 3. Hospital 4. Residential Home 5. Other
13.31	Who paid for this service	0. Personal payment 1. Caregiver 2. Insurance 3. Residential Home

		4. DHB 5. ACC
Section 14	**Therapies / Equipment**	
14.01	Oxygen	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.02	Respirator for assistive breathing	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.03	All other respiratory treatments	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.04	Alcohol/drug treatment Programme	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.05	Blood transfusion(s)	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.06	Chemotherapy	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.07	Dialysis	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence

		3. Scheduled, not received
14.08	IV-infusion-general	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.09	IV infusion – peripheral	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.10	Medication by injection	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.11	Ostomy care	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.12	Radiation	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.13	Tracheostomy care	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.14	Exercise therapy	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received

14.15	Occupational therapy	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.16	Physiotherapy	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
Now I wish to know if you attend any of the following and if you attend as often as they have asked you to.		
14.17	Day centre	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.18	How many days in the past 14 days did you spend at a day centre	_______ days
14.19	Day hospital	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.20	How many days in the past 14 days did you spend at a day hospital	_________days
14.21	Hospice care	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.22	Doctor or clinic visit	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received

14.23	Respite care	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.24	Does a nurse at your home or day centre monitor some aspect of your care everyday (e.g. ECG, Urinary output)	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.25	Does a nurse monitor your care at any time?	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.26	Do you wear a Medical alert bracelet or electronic security alert	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.27	Have you had Skin treatment in the last week	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
14.28	Have you been on a Special diet in the last week	0. Not applicable 1. Scheduled, full adherence 2. Scheduled, partial adherence 3. Scheduled, not received
Management of Equipment (in last 3 days)		
14.29	Do you use oxygen at home	0. No 1. Yes
14.30	Do you need help with using the oxygen equipment	0. Managed on own 1. Managed on own if laid out or with verbal reminders

		2. Partially performed by others 3. Fully performed by others
14.31	Do you use an IV drip at home	0. No 1. Yes
14.32	How are you managing with the use of the IV drip set and tubes	0. Managed on own 1. Managed on own if laid out or with verbal reminders 2. Partially performed by others 3. Fully performed by others
14.33	Do you have an indwelling catheter	0. No 1. Yes
14.34	How are you managing with the use of the Catheter	0. Managed on own 1. Managed on own if laid out or with verbal reminders 2. Partially performed by others 3. Fully performed by others
14.35	Do you have an Ostomy	0. No 1. Yes
14.36	How are you managing with the use of the Ostomy	0. Managed on own 1. Managed on own if laid out or with verbal reminders 2. Partially performed by others 3. Fully performed by others
Section 15	**Health Services**	
15.01	No. of times admitted to hospital with overnight stay in last 3 months	Enter 0 if none, if more than 9, code 9
15.02	No. of times visited A&E department without an overnight stay in last 3 months	Enter 0 if none, if more than 9, code 9
15.03	Have you had to see a nurse or doctor at short notice in the last 3 months?	Enter 0 if none, if more than 9, code 9

15.04	Have you completed any treatment in the last 3 months	0. No 1. Yes
15.05	Do you feel that you are needing more care now than you did 3 months ago	0. No change 1. Improved- receives fewer support 2. Deteriorated- receives more support
15.06	Due to limited money, have you gone without heating the house, food, medicines, visiting the doctor or home care in the last 3 months	0. No 1. Yes
15.07	Have you had any modifications done to the house to make it easier to live there due to your health or disability in the past 12 months	0. No 1. Yes
15.08		Types of modifications
Ramps		0. No 1. Yes
Lifts		0. No 1. Yes
Hand Rails		0. No 1. Yes
Others		0. No 1. Yes
15.09	What was the approximate cost of the modifications	$______________________
Section 16		**EuroQoL**
16.01	Mobility	1. I have no problems in walking about 2. I have some problems in walking about 3. I am confined to bed

16.02	Self-care	1. I have no problems with self-care 2. I have some problems washing or dressing myself 3. I am unable to wash or dress myself
16.03	Usual Activities	1. I have no problems with performing my usual activities 2. I have some problems with performing my usual activities 3. I am unable to perform my usual activities
16.04	Pain/Discomfort	1. I have no pain or discomfort 2. I have moderate pain or discomfort 3. I have extreme pain or discomfort
16.05	Anxiety/Depression	1. I am not anxious or depressed 2. I am moderately anxious or depressed 3. I am extremely anxious or depressed
16.06		Looking at the thermometer scale, on which the best state you can imagine is marked 100 and the worse state you can imagine is marked 0, please indicate how your own health is today
Section 17		**Medications**
17.01	Number of Medications	If none code 0, if more than 9, code 9.
17.02	Receipt of Psychotropic Medication	0. No 1. Yes
17.03	Type of Psychotropic medication	0. Antipsychotic/neuroleptic 1. Anxiolytic 2. Antidepressants 3. Hypnotic
17.04	How many times did you visit the pharmacy to get medicines in last 3 months	___________

17.05	How much money do you spend on medications on average at each visit to the pharmacy	$______________
17.06	In the last 6 months, has a doctor reviewed all medications	0. Discussed with at least one doctor (or no medication taken) 1. No single doctor reviewed all medications
17.07	Have you taken all of the medication prescribed by your doctor in the last week	0. Always compliant 1. Compliant 80% of time or more 2. Compliant less than 80% of time, including failure to purchase prescribed medications 3. No medications prescribed
List prescribed and non-prescribed medications taken in Last 7 Days		
17.08	Medication 1	
17.09	Name	
17.10	Dose	
17.11	Unit	
17.12	Dispensing Date	

Table A.6.1: OPERA variables' relationship with 'time to residential care entry' (N=131)

Variables	T_1 Pearson's r	T_2 Pearson's r
Knowledge of community support	0.163	0.455**
Family support available	0.066	-0.242
Efficacy	0.010	-0.250
Concern family doing too much	0.244**	0.021
Concern about money	-0.041	-0.208
Concern about falling	0.157	-0.095
Concern about burglary	0.032	nil
Concern about housing	0.506**	0.059
Concern about coping	0.208*	-0.080
Concern about being lonely	0.015	-0.110
Concern about health	0.315**	-0.027
Concern about shopping	0.101	nil
Concern about community support	0.292**	0.061
Concern about family support	0.147	-0.001

T = interviews, 1 = initial, 2 = six month, p = significance, ** = $p < 0.01$, * = $p < 0.05$, nil = data incomplete

Table A.6.2: ASPIRE variables' relationship with 'time to residential care entry' (N=569)

Variables	T_0	T_1	T_2	T_3	T_4
	Pearson's r	Pearson's r	Pearson's r	Pearson's r	Pearson's r
Instrumental activities of daily living scale	-0.190**	-0.378**	-0.422**	-0.438**	-0.402**
Activities of daily living scale	-0.102**	-0.286**	-0.292**	-0.277**	-0.259**
Cognitive performance scale	-0.123**	-0.217**	-0.245**	-0.236**	-0.238**
Not seeing neighbours	0.008	0.130**	0.180**	0.212**	0.274**
Not being home alone	0.013	0.181**	nil	0.282**	0.384**
Child not living near	-0.008	-0.113*	-0.081	-0.165**	-0.212**
CHESS	-0.130**	-0.178**	nil	-0.113*	-0.147
Pain scale	-0.013	0.051	0.060	0.103*	-0.004
Family not living near	-0.091	-0.093*	nil	-0.054	0.247**
Depression scale	-0.087	-0.114*	-0.173**	-0.050	-0.215**
Caregiver stress	-0.127*	-0.054	-0.066	0.192*	0.157
Hospital admission	0.021	-0.053	-0.97*	-0.054	0.058
Lonely	-0.054	-0.061	nil	0.010	-0.008
Sibling not living near	0.013	0.016	0.026	0.032	0.007
Friend not living near	0.025	0.051	0.020	-0.096	-0.031

CHESS = Changes in health, end-stage disease and signs and symptoms, p = significance, ** = $p < 0.01$, * = $p < 0.05$

T = interview, 0 = initial, 1 = 3 month, 2 = 6 month, 3 = 12 months, 4 = 18 month, nil = data incomplete for that interview

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