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Ageing Baby Boomers: Mid-life adults’ attitudes, plans and expectations of their future ageing in New Zealand

Helen Ann Malcolm

A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy
The University of Auckland
2012
Abstract

Objective: To gain an understanding of how the experiences of caring for an older person had influenced mid-life adults attitudes to ageing, plans and expectations of the own future older years, including housing, finances and health, and how their support needs might be met. Additionally, consideration of how whether the New Zealand Government funding for the nursing and carer workforce to support services for older people met the policies aimed at addressing the needs of the ageing population.

Design: Sequential mixed methods design.

Setting: Auckland, a city of 1.5 million people and the largest urban area in New Zealand.

Participants and methods: Six focus groups attracted 36 participants, all met the criteria age range of 40-64 years, with 33 women and three men. Eight of the participants identified as Māori while the other 25 were predominately New Zealanders of European descent. The five interviewees were all women. The 127 postal survey respondents were also within the 40-64 years age range with a total of 83 females and 44 males. Ethnicity of respondents’ included Māori, Pacific Island, Asian and Indian with the greatest number being New Zealand European.

Results: The results identified motivation for mid-life adults’ support of older relatives, nature of assistance, caregiver stress, and difficulties accessing formal support services. Participants revealed concern about retirement housing suitability, financial preparedness, and health with respect to future ageing. While they expressed the wish to not burden younger relatives with their ageing care needs they also communicated the desire to live close to family as they aged with the hope of receiving support should this be need in the future. Many participants revealed an unwavering expectation of state-funded support for their age-related functional needs and residential care based on the premise of recompense for years of paying taxes.

Conclusions: The findings have revealed significant implications for the families of the ageing population as well as the New Zealand government agencies committed to provide the disability support services for older people that will enable them to continue living independently. The perceived inadequacy of support services and nursing and careworker personnel to provide care may leave many older people reliant on relatives to support their daily functional activities. With many younger family members engaged in paid employment and managing their own family’s needs such expectations are unrealistic, meaning older people will make increasing demands on a limited disability support service. The apparent dislocation between government policies, funding of disability support services, and the inadequate numbers of nurses and carerworkers points to a significant challenge for the provision of services that meet the needs of the increasing numbers of older people both currently and into the future.
Acknowledgements

I would like to begin by expressing my sincere thanks to the many participants in the study who have generously given of their time to share their thoughts and experiences in relation to caring for an older person or ideas about their future ageing. A special thank you goes to the focus group participants and individual interviewees who were willing to share their personal stories of supporting an older person and the joys, challenges and anxieties presented by these experiences. It has been a privilege to hear your stories and thoughts on ageing.

My appreciation also goes to Dr Lorna Dyall who identified potential participants and facilitated the Māori focus group. Her interest and enthusiasm resulted in a lively group who made a meaningful contribution to the project. Thank you also to Dr Deborah Rowe who read and endorsed the analysis of the Māori focus group data.

I would like to acknowledge the important contribution of my supervisors who have supported and challenged me throughout this journey of discovery and learning: Dr Robyn Dixon for looking at the big picture and questioning the theoretical foundations and processes as the project progressed, and Dr Diane Jörgensen for her advice and attention to detail to my writing. Their guidance and support has been invaluable in enabling me to achieve the goals of this study. I would also like to thank Lorraine Nielsen for her patience and expertise with regard to the referencing.

Last but not least, my family; Chris, Kate and David, and my mother, deserve my heartfelt gratitude for their unwavering support during this long process of study and writing. They have tolerated my grumpy moods and distraction, and celebrated each small success along the way. Their continual encouragement, particularly Chris for his willingness to listen and engage in endless conversations about the study, has made the journey more manageable.
# Table of Contents

Abstract i
Acknowledgements iii

Chapter 1: Introduction 1
1.1 Research Interest 3
1.2 Research Objectives 6

Chapter 2: Review of the Literature 9
Introduction 9
2.1 Literature Search 10
2.2 International trends on ageing 10
2.3 New Zealand Government policies on the ageing population 11
  2.3.1 Current policies and funding for older peoples’ support services 12
  Government policies 12
  Government-funded health care services 13
  Ministry of Health targets for improving population health 13
  Accident Compensation Corporation funding for older people 13
  Privately-funded healthcare 14
  2.3.2 Future planning and direction 15
2.4 Quality of life and factors impacting on ageing 15
  2.4.1 Health, Illness and Disability 16
  Healthy Ageing 17
  Life satisfaction and resilience 17
  Ageing and frailty 18
  Musculoskeletal changes and disability 18
  Programmed exercise to promote physical independence 18
  2.4.2 Financial Factors 19
  Financial provision for retirement 19
  Poverty in old age 20
  Financial preparedness for retirement 21
  2.4.3 Independence at home and community-based supports 23
  Need for support services 24
  Social interaction and life satisfaction 24
  Family relationships and co-residence 25
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.5 Intergenerational influences and values in caring for older relatives</td>
<td>26</td>
</tr>
<tr>
<td>2.5.1 Reciprocity within family relationships</td>
<td>27</td>
</tr>
<tr>
<td>2.5.2 Caring for older relatives</td>
<td>27</td>
</tr>
<tr>
<td>2.5.3 Competing demands of the Sandwich generation</td>
<td>29</td>
</tr>
<tr>
<td>2.6 Stress and burden associated with caring for older relatives</td>
<td>30</td>
</tr>
<tr>
<td>2.6.1 Level of support required to meet the older person’s needs</td>
<td>30</td>
</tr>
<tr>
<td>2.6.2 Sibling relationships and sharing care provision</td>
<td>31</td>
</tr>
<tr>
<td>2.6.3 Safety risks for older people living alone</td>
<td>32</td>
</tr>
<tr>
<td>2.7 Factors influencing entry to residential care among older people</td>
<td>32</td>
</tr>
<tr>
<td>2.8 The ageing Baby Boomer generation</td>
<td>33</td>
</tr>
<tr>
<td>2.8.1 Social changes for Baby Boomers across the life span</td>
<td>33</td>
</tr>
<tr>
<td>2.8.2 Expectations of ageing Baby Boomers</td>
<td>34</td>
</tr>
<tr>
<td>2.8.3 Preferences in housing for the ageing Baby Boomers</td>
<td>34</td>
</tr>
<tr>
<td>2.8.4 Potential impact on aged care services</td>
<td>36</td>
</tr>
<tr>
<td>Conclusion</td>
<td>37</td>
</tr>
</tbody>
</table>

**Chapter 3: Life Course Perspective Theory**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>39</td>
</tr>
<tr>
<td>3.1 Exploration of theoretical frameworks</td>
<td>39</td>
</tr>
<tr>
<td>3.2 Life Course Perspective Theory</td>
<td>40</td>
</tr>
<tr>
<td>3.2.1 Life-span trajectories and role expectations</td>
<td>43</td>
</tr>
<tr>
<td>3.2.2 Relationships and family influences</td>
<td>44</td>
</tr>
<tr>
<td>Conclusion</td>
<td>45</td>
</tr>
</tbody>
</table>

**Chapter 4: Methodology and Methods**

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>47</td>
</tr>
<tr>
<td>4.1 Methodology</td>
<td>47</td>
</tr>
<tr>
<td>4.1.1 Mixed Method Research</td>
<td>48</td>
</tr>
<tr>
<td>Triangulation</td>
<td>50</td>
</tr>
<tr>
<td>4.1.2 Qualitative Research</td>
<td>52</td>
</tr>
<tr>
<td>Focus Groups and face-to-face interviews</td>
<td>54</td>
</tr>
<tr>
<td>4.1.3 Quantitative Research</td>
<td>56</td>
</tr>
<tr>
<td>Surveys</td>
<td>56</td>
</tr>
<tr>
<td>4.2 Methods</td>
<td>57</td>
</tr>
<tr>
<td>4.2.1 Phase One Focus Groups and Interviews</td>
<td>58</td>
</tr>
<tr>
<td>Ethical considerations</td>
<td>58</td>
</tr>
<tr>
<td>Sample Recruitment</td>
<td>58</td>
</tr>
</tbody>
</table>
Data Collection: Focus Groups 60
Data Collection: Face-to-face interviews 61
Data Analysis 62
Reliability and trustworthiness 62
4.2.2 Phase two: Descriptive Survey 64
Development of Questionnaire 64
Pilot Study 66
Ethical considerations 66
Sampling size justification 66
Sample Recruitment 67
Data Collection 69
Data Analysis 69
Reliability and validity 70
Conclusion 71

Chapter 5: Focus Group and Interview Findings 72
Introduction 72
5.1 Participant Characteristics 73
5.2 Experiences of caring for an older person 77
5.2.1 Attitudes to older people 77
5.2.2 Supporting the independently-living older person 78
Increasing need for support services 79
Safety concerns for the older person 79
5.2.3 Accessing formal support for the older person 81
Regional variations in support services 82
Appropriate support services for older people with dementia 83
Older person’s coping with service careworkers 84
ACC and Palliative care support services 84
5.2.4 Stresses for adult children in supporting the older person 85
The changing relationship between the older person and adult child 86
Conflicting commitments for mid-life adults 86
5.2.5 Variations and issues in family support of the older person 88
Lack of family support contributed to mid-life adults’ experience of stress 89
Positive experiences in supporting the older person 90
5.2.6 Māori perspectives on caring for older people 91
The impact of colonisation on Māori 92
The sense of a fractured family structure 93
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.2.7 The hospital admission experience</td>
<td>94</td>
</tr>
<tr>
<td>Standards of hospital care received by the older person</td>
<td>94</td>
</tr>
<tr>
<td>Services for older people’s health</td>
<td>95</td>
</tr>
<tr>
<td>Managing the older person’s discharge from hospital</td>
<td>96</td>
</tr>
<tr>
<td>Learning about support services entitlements</td>
<td>96</td>
</tr>
<tr>
<td>5.3 The multi-generational household and family relationships</td>
<td>97</td>
</tr>
<tr>
<td>5.3.1 Circumstances leading to multi-generational living arrangements</td>
<td>97</td>
</tr>
<tr>
<td>Long-term multi-generational co-residence</td>
<td>98</td>
</tr>
<tr>
<td>5.3.2 Relationships in the multi-generational household</td>
<td>99</td>
</tr>
<tr>
<td>The importance of the mid-life adults’ partner in support of the older person</td>
<td>100</td>
</tr>
<tr>
<td>Special memories and interpersonal relationships</td>
<td>100</td>
</tr>
<tr>
<td>Tension in family relationships</td>
<td>101</td>
</tr>
<tr>
<td>5.3.3 Children’s involvement in caring for the older person</td>
<td>102</td>
</tr>
<tr>
<td>Sharing household responsibilities</td>
<td>102</td>
</tr>
<tr>
<td>Grandchildren assisting their grandparents</td>
<td>103</td>
</tr>
<tr>
<td>Protecting grandchildren from caring duties</td>
<td>104</td>
</tr>
<tr>
<td>5.4 Participants’ considerations for future ageing</td>
<td>105</td>
</tr>
<tr>
<td>5.4.1 Participant’s plans and ideas for their future ageing</td>
<td>105</td>
</tr>
<tr>
<td>Anticipation of longevity</td>
<td>105</td>
</tr>
<tr>
<td>The importance of physical health and well-being</td>
<td>106</td>
</tr>
<tr>
<td>Maintaining mental health and cognitive functioning</td>
<td>107</td>
</tr>
<tr>
<td>Housing preferences</td>
<td>108</td>
</tr>
<tr>
<td>Co-habitating with friends and siblings</td>
<td>109</td>
</tr>
<tr>
<td>Communal housing and retirement villages</td>
<td>110</td>
</tr>
<tr>
<td>5.4.2 Prospects of support from the younger generation</td>
<td>112</td>
</tr>
<tr>
<td>Companionship from grandchildren</td>
<td>113</td>
</tr>
<tr>
<td>Modelling the caregiver role</td>
<td>113</td>
</tr>
<tr>
<td>Recognition of potential responsibilities for adult children</td>
<td>114</td>
</tr>
<tr>
<td>Participants’ desire not to be a burden to their adult children</td>
<td>115</td>
</tr>
<tr>
<td>Expectations of government-funded support services</td>
<td>116</td>
</tr>
<tr>
<td>Hopeful expectations of future support from adult children</td>
<td>116</td>
</tr>
<tr>
<td>Conclusion</td>
<td>118</td>
</tr>
<tr>
<td>Chapter 6: Insights into the complexity of aged-care through family stories</td>
<td>120</td>
</tr>
<tr>
<td>Introduction</td>
<td>120</td>
</tr>
<tr>
<td>6.1 Clare’s family story</td>
<td>121</td>
</tr>
<tr>
<td>Clare’s reflections on future ageing</td>
<td>124</td>
</tr>
<tr>
<td>Section</td>
<td>Page</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Clare’s Family Tree</td>
<td>125</td>
</tr>
<tr>
<td>6.2 Jenny’s family story</td>
<td>126</td>
</tr>
<tr>
<td>Jenny’s reflections on future ageing</td>
<td>128</td>
</tr>
<tr>
<td>Jenny’s Family Tree</td>
<td>129</td>
</tr>
<tr>
<td>6.3 Anne’s family story</td>
<td>130</td>
</tr>
<tr>
<td>Anne’s reflections on future ageing</td>
<td>131</td>
</tr>
<tr>
<td>Anne’s Family Tree</td>
<td>133</td>
</tr>
<tr>
<td>6.4 Pam’s family story</td>
<td>134</td>
</tr>
<tr>
<td>Pam’s reflections on future ageing</td>
<td>135</td>
</tr>
<tr>
<td>Pam’s Family Tree</td>
<td>137</td>
</tr>
<tr>
<td>6.5 Suzanne’s family story</td>
<td>138</td>
</tr>
<tr>
<td>Suzanne’s reflections on future ageing</td>
<td>139</td>
</tr>
<tr>
<td>Suzanne’s Family Tree</td>
<td>141</td>
</tr>
<tr>
<td>Conclusion</td>
<td>142</td>
</tr>
<tr>
<td>Chapter 7: Survey Findings</td>
<td>144</td>
</tr>
<tr>
<td>Introduction</td>
<td>144</td>
</tr>
<tr>
<td>7.1 Respondent Characteristics</td>
<td>144</td>
</tr>
<tr>
<td>7.2 Experience of caring for an older person</td>
<td>148</td>
</tr>
<tr>
<td>7.3 Planning for ageing years</td>
<td>152</td>
</tr>
<tr>
<td>Conclusion</td>
<td>159</td>
</tr>
<tr>
<td>Chapter 8: Discussion</td>
<td>160</td>
</tr>
<tr>
<td>Introduction</td>
<td>160</td>
</tr>
<tr>
<td>8.1 The experiences of caring for an older person</td>
<td>162</td>
</tr>
<tr>
<td>Caregiver stress</td>
<td>162</td>
</tr>
<tr>
<td>Māori participants’ perspectives</td>
<td>164</td>
</tr>
<tr>
<td>Disability support services</td>
<td>165</td>
</tr>
<tr>
<td>8.2 Expectations and plans for future age-care</td>
<td>166</td>
</tr>
<tr>
<td>Health and independence</td>
<td>167</td>
</tr>
<tr>
<td>Financial considerations</td>
<td>169</td>
</tr>
<tr>
<td>Housing options</td>
<td>170</td>
</tr>
<tr>
<td>Family support</td>
<td>171</td>
</tr>
<tr>
<td>8.3 Study strengths and limitations</td>
<td>172</td>
</tr>
<tr>
<td>Conclusion</td>
<td>173</td>
</tr>
<tr>
<td>Section</td>
<td>Page</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>Chapter 9: Implications and Recommendations</td>
<td>176</td>
</tr>
<tr>
<td>Introduction</td>
<td>176</td>
</tr>
<tr>
<td>9.1 Family support for older people</td>
<td>177</td>
</tr>
<tr>
<td>9.2 Support services for older people</td>
<td>178</td>
</tr>
<tr>
<td>9.3 Nurses and support workers for the care of older people</td>
<td>180</td>
</tr>
<tr>
<td>9.4 Recommendations</td>
<td>182</td>
</tr>
<tr>
<td><em>Improved access to appropriate disability support services for older people</em></td>
<td>182</td>
</tr>
<tr>
<td><em>Suitable and affordable housing for older people</em></td>
<td>182</td>
</tr>
<tr>
<td><em>Support of family caregivers of older people</em></td>
<td>183</td>
</tr>
<tr>
<td><em>Recognition of the aged-care nursing and carer workforce</em></td>
<td>183</td>
</tr>
<tr>
<td><em>Financial planning for retirement</em></td>
<td>183</td>
</tr>
<tr>
<td>9.4 Future Research opportunities</td>
<td>183</td>
</tr>
<tr>
<td>Summary</td>
<td>184</td>
</tr>
<tr>
<td>Appendices</td>
<td>185</td>
</tr>
<tr>
<td>References</td>
<td>214</td>
</tr>
</tbody>
</table>
List of Tables

4.1 95% confidence interval widths for different percentages and 300 respondents 66
4.2 Selection of postal survey respondents 67
4.3 Flow chart of participant recruitment 68
5.1 Age, Gender and Ethnicity of the Focus Groups Participants 73
5.2 Analysis of Focus Groups and Interviews data using NVivo8 74
7.1 Gender and Age Distribution of Respondents by Number and Percentage 145
7.2 Number and Percentage of Respondents by Gender and Ethnicity 145
7.3 Respondents' Employment Status and Additional Caring Role 146
7.4 Respondents' Household Characteristics 147
7.5 Number and Ages of Children Living with Respondents 147
7.6 Respondents' Self-rated Health and Fitness 148
7.7 Type of Assistance and Frequency of Provision by Respondents to the Older Person 149
7.8 Respondents' Rating of Motivation for Supporting the Older Person 150
7.9 Respondents' Rating of the Experience of Providing Support to the Older Person 151
7.10 Respondents' Choice of Responsibility for Age-related Care Provision 154
7.11 Factors Influencing Respondents' Choice of Age-related Supports 155
7.12 Respondents' Options for Living Locality in Their Older Years 156
7.14 Respondents' Choice of Person Most Likely to Support Their Ageing Needs 158
# List of Appendices

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>University of Auckland Ethics application approval</td>
<td>185</td>
</tr>
<tr>
<td>2</td>
<td>Participant Information Sheet: Focus Group</td>
<td>186</td>
</tr>
<tr>
<td>3</td>
<td>Participant Information Sheet: Individual Interview</td>
<td>188</td>
</tr>
<tr>
<td>4</td>
<td>Advertisement printed in the <em>Aucklander</em> newspaper</td>
<td>190</td>
</tr>
<tr>
<td>5</td>
<td>Poster advertising study for display in Community Organisations</td>
<td>191</td>
</tr>
<tr>
<td>6</td>
<td>Focus Group Information to Manakau City Council employees</td>
<td>192</td>
</tr>
<tr>
<td>7</td>
<td>Letter to the University of Auckland Human Ethics Committee</td>
<td>193</td>
</tr>
<tr>
<td>8</td>
<td>Letter of support from the Tumuaki of the Faculty of Medical and Health Sciences, University of Auckland</td>
<td>194</td>
</tr>
<tr>
<td>9</td>
<td>Letter of approval from the University of Auckland Human Ethics Committee</td>
<td>195</td>
</tr>
<tr>
<td>10</td>
<td>Consent Form: Focus Group</td>
<td>196</td>
</tr>
<tr>
<td>11</td>
<td>Consent Form: Individual Interview</td>
<td>197</td>
</tr>
<tr>
<td>12</td>
<td>Focus Group Guideline and Discussion Prompts</td>
<td>198</td>
</tr>
<tr>
<td>13</td>
<td>Individual Interview: Conversation Prompts</td>
<td>199</td>
</tr>
<tr>
<td>14</td>
<td>Transcriber Confidentiality Agreement</td>
<td>200</td>
</tr>
<tr>
<td>15</td>
<td>Survey Questionnaire</td>
<td>201</td>
</tr>
<tr>
<td>16</td>
<td>Survey Participant Information Sheet</td>
<td>209</td>
</tr>
<tr>
<td>17</td>
<td>Ministry of Health Northern X Regional Ethics Committee application approval</td>
<td>211</td>
</tr>
<tr>
<td>18</td>
<td>Survey Information to City Council employees</td>
<td>213</td>
</tr>
</tbody>
</table>
# List of Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACC</td>
<td>Accident Compensation Corporation</td>
</tr>
<tr>
<td>ADHB</td>
<td>Auckland District Health Board</td>
</tr>
<tr>
<td>ASPIRE</td>
<td>Assessment of Services Promoting Independence and Recovery in Elders</td>
</tr>
<tr>
<td>CVD</td>
<td>Cardiovascular Disease</td>
</tr>
<tr>
<td>DHBs</td>
<td>District Health Boards</td>
</tr>
<tr>
<td>DM</td>
<td>Diabetes Mellitus</td>
</tr>
<tr>
<td>DSS</td>
<td>Disability Support Services</td>
</tr>
<tr>
<td>FG</td>
<td>Focus Group</td>
</tr>
<tr>
<td>GDG</td>
<td>Gross Domestic Growth</td>
</tr>
<tr>
<td>GDP</td>
<td>Gross Domestic Profit</td>
</tr>
<tr>
<td>MoH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>MSD</td>
<td>Ministry of Social Development</td>
</tr>
<tr>
<td>NASC</td>
<td>Needs Assessment Service Coordination</td>
</tr>
<tr>
<td>OECD</td>
<td>Organisation for Economic Development</td>
</tr>
<tr>
<td>OPERA</td>
<td>Older People Entering Residential Accommodation</td>
</tr>
<tr>
<td>PRCS</td>
<td>Primary Health Care Strategy</td>
</tr>
<tr>
<td>PHO</td>
<td>Primary Health Organisations</td>
</tr>
<tr>
<td>RVA</td>
<td>Retirement Village Association</td>
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Chapter 1

Introduction

The ability to continually assess strengths, modify lifestyles, and redefine oneself was identified by multiple ethnographic research studies as the core of healthy aging. (Hansen-Kyle, 2005, p. 48)

Healthy ageing has been defined as having the attributes of resilience, independence, physical and psychological functioning and the ability to make decisions about lifestyle and care options (Gabriel & Bowling, 2004; Hansen-Kyle, 2005; Koch, Power, & Kralik, 2007; van Maanen, 2006). With a growing older population there are potential expectations for the extended families, support services, housing, and government planning, funding and workforce development to meet the needs of these older people. Exploring these issues with older people of the future is the basis of this study.

Following World War II, during the years from 1946 to 1964, the birth rate in many Western Countries increased significantly, resulting in a population bulge commonly called the “Baby Boomer” generation (Quine & Carter, 2006, p. 3; Rogerson & Kim, p. 15319). The result of this phenomenon has been considerable social change necessitating governmental planning to anticipate the needs of education, housing and healthcare services as the Baby Boomers have progressed through life (Rogerson & Kim, 2005). There is an expectation that societal adjustment will continue as this population bulge transitions into older age and retires from active employment (Longino, 2005). The oldest members of this cohort are now reaching the retirement years and while many will continue to lead an active social life with the expectation of a reasonable state of health, it can realistically be predicted that their individual requirements, particularly in housing and health, will need to change in the future to accommodate their ageing (Jörgensen, 2007; Wood, Colic-Peisker, Berry, & Ong, 2011).

Census data and the literature indicates that New Zealand is following the same trends as other Western, industrialised, countries with an ageing population and the expectation of significant growth in the over 65 year age group (Booth, Miller, & Mor, 2007; Dunstan, 2006; Pink, 2004; Statistics New Zealand, 2007a; World Health Organisation, 2007). The increased birth rate during the years 1950-1970 was the most outstanding aspect of New Zealand’s demography (Dunstan, 2006). This increase in births has resulted in the
population share of people aged 65 years and older having doubled since 1970 at a time when the total population had only increased by 44 percent (Dunstan & Thomson, 2006). By 2030, the number of people aged 65 and older is expected to exceed 25 percent of the total population of New Zealand with the oldest 10 percent likely to be aged over 81 years by 2051 (Anderson & Hussey, 2000; Dunstan, 2006; Pink, 2004). The projected figures also indicate that life expectancy at birth will increase to 83.5 years for men and 87.0 years for women by 2051. The New Zealand population has exceeded four million with an increase in the median age from 33.0 to 35.9 years over the 20 year period from 1996 to 2006, reflecting the ageing of the population (Statistics New Zealand, 2007a).

The estimated healthy life expectancy, the years of life a person can expect to live in a reasonable state of health, has increased slightly in recent years to 67.4 years for males and 69.2 for females (Ministry of Health [MoH], 2011a). Dependency ratios are significant when considering the support needs of the future older people in New Zealand. The projected dependency ratios suggest that the younger cohort of dependents (aged 0-14 years) will be greater than the older cohort (aged over 65 years) in 2011, however by 2051 the dependence ratio will reverse with 53 percent in the older age group (Dunstan, 2006).

Projections for dependency and increased longevity in the older age group, coupled with the low birth rate, have implications for the future provision of formal and informal support, and also, the human resources and funding to provide these services. Alongside the uncertainty of population projections is the limited knowledge of how this ageing population will fare in terms of health, functional capacity, financial security and expectations of family and the government for support. Although reported disability figures have dropped from 20 percent in 2001 to 17 percent in 2006, there is evidence of an increasing occurrence of chronic illnesses which represents a significant demand on the limited healthcare and disability resources funded by the government’s health budget (Ministry of Health, 2011a).

In recognition of the increasing ageing population in Western society a study commissioned by the World Health Organisation (WHO) on global ageing and adult health (SAGE) aimed to explore health, well-being, trends and life events, and to provide information for policy makers and health systems planners related to older people (WHO, 2007). The underlying premise of SAGE is the realisation that the growth of an ageing population has serious implications for governmental policy, financial planning and infrastructure support, both now and in the future.
The following study was designed to explore the expectations of people ageing in New Zealand with respect to aged care needs and services, with a view to contributing to the meagre body of knowledge currently focus groups and face-to-face interviews, and the second consisting of an anonymous survey. The target population for the study was mid-life adults; those known as the Baby Boomers and currently aged between 40 and 64 years.

The use of mixed methods is a well-recognised process of studying specific phenomena from different perspectives (Bergman, 2010). For this study, the interpretive design was employed initially to explore individuals’ experiences, perceptions and expectations of caring for an older person (Polit, Beck, & Hungler, 2001). Applying an interpretative approach meant engaging with people in focus groups and face-to-face interviews to learn about their experiences and gain an understanding of the implications of supporting ageing relatives or friends. The process also provided insights into how these experiences influenced participants' expectations of their own future ageing. The first phase findings contributed to the development of a survey which was implemented to explore the issues with a greater number of people who represent the target population. The findings from each phase were combined in the discussion which is linked to the literature and government policies, planning, funding, and nursing workforce development for the growing population of older adults in New Zealand.

1.1 Research Interest

A recognised premise of the nursing profession is that “caring forms the core of nursing actions” (Cheung, 1998, p. 225). Interacting with clients and their families as a nurse enables observation of the caring relationship between generations. Such reciprocity has been recognised as forming the fabric that links individuals and ensures they continue to be a family despite geographical separation, career demands, and nuclear family or social commitments (Keeling, 2001; Sebern, 2005; Wall & Spira, 2006). Working with older people and their families in a hospital setting has led to an interest in how people adapt and plan for old age. Observing the challenges faced by the younger family members when assisting their older relatives and the comments they made about ageing has, in turn, led to an aspiration to understand how mid-life people perceive their old age will be shaped, and who will support their needs in the later years of their lives.

Gillis and Perry (1991) regarded this midlife period as a time for evaluating your life and looking toward the future, especially considering health and lifestyle. It is an age where
Introduction

looking backwards over the years, and forwards to the unknown future allows a broader view of life. For many mid-life adults it is time involvement with ageing parents and the emergence of children as independent adults. A very apt term used to describe this place on the life continuum is the ‘sandwich generation’ (Brett, 1999; Grundy & Henretta, 2006). The phrase lays claim to a position of providing emotional and monetary support to the “ascending and descending” generations within the family, especially as longevity ensures the advent of three or four generations alive at one time (Grundy & Henretta, 2006, p. 707). The mid-life, middle generation position presents many challenges from the preceding and ensuing generations.

My role as a Clinical Charge Nurse in a New Zealand regional hospital assessment, treatment and rehabilitation ward for older people heightened an awareness of difficulties for both the older person, as their independence diminishes, and the relatives who support them. The primary focus of the rehabilitation service was to assist the older person to regain their independence and functional capacity following physical decline secondary to a medical or surgical event (Cameron & Kurrie, 2002). In this setting, health professionals sought ways of enabling the individual to recover function lost through a period of illness or declining health, and resume their former level of independence. Inevitably, relatives, friends and even neighbours became known to the healthcare team as they voiced their perceptions of how the older person was coping at home. In most cases, the older person existed in a wider family context and relied on relatives’ support, both emotional and practical, to live independently, however, a few individuals led a solitary existence, lacking either the functional or psychological support of relatives, friends, or a meaningful social network.

Many family members of the older patients revealed the wide ranging dilemmas and anxiety experienced as they coped with their parents’ ageing and increased frailty. The sons and daughters were grappling with the knowledge that their parents were facing an uncertain future in terms of health, housing, finances and support needs. Much of the concern expressed related to fears for the older person’s personal safety, especially the risk of falling and sustaining injuries. They also identified issues with the older person remembering to take prescribed medication and managing their daily needs such as food and hygiene. Often the family assistance, particularly with shopping and house maintenance, had gradually increased over a period of months or years. However, the incident that necessitated their parent’s admission to hospital became a catalyst for considering the feasibility of the parent continuing to remain in their own home. The options considered to manage the older
person’s increased needs ranged from providing more support in the home, changing residence to live with family, or admission to a residential care facility.

Discussions with the older clients made it apparent that most would prefer to remain living independently in their own home. The desire to maintain their independence is understandable after a life-time of raising a family, working and managing their own everyday existence. Often the older person expressed resentment toward what they perceived as interference from family and a threat to their autonomy. They also indicated how much they appreciated the interest and support they received from their children, revealing the tension between the need for assistance and the desire to maintain their independence. At times, the family meetings, arranged to discuss issues of support and care needs, exposed the tensions between the older person's wishes and the adult children's apprehension for their parent. Observation of families has highlighted the stressful nature of caring for ageing parents and striving to ensure safety while respecting the older person's right to make their own choices.

Adult children frequently commented on the support they tried to offer their mother or father, the overwhelming sense of duty, and the impact this had on their relationship with the parent and other relatives. A common thread of discord was the varying perspectives of siblings regarding their parents care needs. These adult children of the patients would voice their anxieties, including disagreement with their siblings and seeking support for the most appropriate course of action to achieve the best solution for their parent. Such revelations displayed the adult child’s perceptions regarding their parent; particularly when they considered their older person’s safety was at risk and daily needs were not being adequately met. Conflict regarding the older person’s needs was evident between siblings as well as parent and child, leading to challenging family meetings.

The role of the family in supporting their older relative to remain at home cannot be underestimated. I noted that it was often the informal support provided by the sons, daughters and grandchildren, augmented by formal support services, which enabled many older people to retain a relatively independent existence in the community. The growth of the support role can be insidious as the individual needs of the older person may gradually change with natural ageing and various physical or mental health conditions. Family members clearly accepted a caring, supportive role toward older relatives and increasing responsibility for their overall welfare, even when undertaking such a role impacted on family dynamics. However, family relationships are complex, no more so than when
intergenerational differences are involved. Arguments often arose when the older patient appeared to have lost the insight to recognise their changing needs and refused to accept suggestions by relatives for better management at home. Talking with the family members of patients in the rehabilitation ward revealed the enormous strain many of these people dealt with and the dilemmas they faced every day in supporting their ageing relatives.

Interaction with older people and their younger family members has fostered a consciousness of the problems faced by ageing and increased frailty. The wider considerations, including the need for instrumental and psychological support, emotional and financial impact on the family, and health sector service provision, have highlighted the implications for this group of the population. It was evident that many older people lacked foresight into the consequences of ageing and therefore had not planned for their future needs.

These clinical observations have led to many questions regarding the future landscape of ageing and support for the current middle-aged population in New Zealand. For example, what factors do individuals consider when choosing their housing arrangements after their children have left home? What are their expectations of supporting their ageing parents, or receiving support from their own children? Exploring these matters through the eyes of people in the generation prior to what is considered old age will provide some indication of how this landscape may be shaped for them. Furthermore, gaining an understanding of how past experiences, family traditions and personal aspirations lead to choice and planning may also contribute to a greater depth of knowledge regarding the impending needs of Baby Boomers as they move into the older age sector of the population.

1.2 Research Objectives

While the catalyst for such questions was the interactions with older people the focus moved to those whose older years are in the near future, more particularly the Baby Boomer generation. Consequently, the question that has driven the study was:

What are the perceptions and expectations of mid-life adults (45-64 years old) in New Zealand regarding their ageing and future support needs?

The two-phase approach was employed to firstly explore the experiences of caring for an older person and subsequent reflections on ageing, followed by a survey applying the
Introduction

questions and issues raised in the initial phase to a wider population group. Both phases were designed to discover the participants’ personal expectations regarding their future ageing. In accordance with the exploratory nature of the study, the first phase involved a small participant group while the second phase aimed to capture the views of the wider target population.

The specific objectives of the study were to explore:

• mid-life adults’ experiences of caring for older people; and
• how the experience of caring for the older person influences mid-life adults’ perceptions and planning for their own future ageing including:
  ° future health, financial planning, housing, and support needs
  ° expectations of filial involvement in their own aged-care needs
• the implications for the healthcare system and nursing workforce of the increasing numbers of older people needing support services

Chapter two reviews the literature with reference to many aspects associated with ageing. Included in the discussion are the New Zealand governmental policies on ageing and support provisions for older people; quality of life and factors impacting on ageing; family and intergenerational influences and values; providing care for older relatives; factors influencing entry to residential care; and the demographic trends in New Zealand.

Chapter three describes the process of determining the theoretical basis of the study and describes the life course perspective theory. The methodology used to explore issues of ageing in New Zealand.

The methodology and methods, including the ethical considerations, data collection and analysis, rigor, validity and trustworthiness applied to the research are detailed in Chapter four.

Chapter five provides the findings of the first phase of the study. The detailed descriptions of the focus groups and interviewees experiences of caring for an older person are illustrated with excerpts from the data.

In Chapter six the interviewees’ stories are presented to allow for a deeper understanding of these individuals’ perceptions and insights and how their thoughts and plans for their own
Introduction

future ageing have been shaped by the experience of caring for older relatives. Each story includes a pictorial depiction of the participant’s family covering four generations.

Chapter seven presents the second phase of the study which utilised a postal survey questionnaire to explore issues raised by participants in first phase of the study.

Chapter eight provides a discussion of the findings from both phases of the study in relation to the available literature and implications for New Zealand government policies and funding in relation to older people and their families, and the provision support services and associated personnel.

Chapter nine concludes the study and presents recommendations aimed at addressing the major issues arising from the study and suggestions for future research relevant to issues of aged-care support services.
Chapter 2

Literature Review

*The inner sense of self is ageless, and continuity of identity is stressed despite the physical and social changes associated with adult ageing.* (Biggs, 2005, p. S120)

Introduction

The United Nations (UN) recognised the complexity of ageing and its effect on society by declaring the year 1999 as the International Year of the Older Person, and also by announcing that ‘changing demography’ would be the theme of the 2002 UN World Assembly (Antonucci, Okorodudu, & Akiyama, 2002). With an interest in global concerns, the UN considered that the demographic change associated with increasing numbers of older people as having a significant impact on social issues worldwide. The stated goals of the 2002 UN World Assembly were that older people should be able to “maintain their independence as long as possible, and to participate energetically in social activities and be allowed to contribute to society in a constructive and productive manner” (Antonucci, et al., 2002, p. 619). This positive affirmation of older people centred on the key elements of dignity, participation, independence, and self-fulfilment, which collectively contribute to an individual’s sense of well-being and quality of life. The older person’s physical health, family and social relationships, and finances underlie these important factors and impact on quality of life (Borg, Hallberg, & Blomqvist, 2006). Consideration must be taken of the way in which health and social networks support or diminish an older person’s capacity to maintain their independence and contribute to society.

The purpose of scrutinising the literature is to compile a comprehensive background; providing an understanding of the issues relevant to the study and identifying the gap in published research that this study aims to address. The following chapter presents a discussion of the literature pertaining older people with respect to intergenerational trends on ageing, New Zealand Government policies and demographic trends, quality of life, the burden of care, entry to residential care and the impact of the Baby Boomer generation on Western society.
2.1 Literature Search

Access to literature relevant to the study undertaken and the issues of ageing was achieved through the following databases: MEDLINE, CINAHL, Journals@Ovid full text, Wiley Interscience (http://www3.interscience.wiley.com/), and Google Scholar (http://scholar.google.co.nz/). The University of Auckland’s Library Voyager – Catalogue was also used. Books were located by manual search at the Philson Library in the Faculty of Medical and Health Sciences at The University of Auckland. New Zealand Government policy documents were accessed through websites including those of the Ministry of Health (MoH) (http://www.moh.govt.nz/), the Ministry of Social Development (http://www.msd.govt.nz/) and Statistics New Zealand (http://www.stats.govt.nz/). Publications from the MoH were used to provide information on government strategies. The key words chosen for the literature search were ‘ageing’ and ‘older people’, and to provide a wide range of sources with which to inform the study the key words were linked with several terms, such as ‘caregiving’, ‘family relationships’, ‘stress and burden’, ‘social and community supports’, ‘quality of life’, ‘retirement’, ‘financial considerations’ and ‘health and illness’. Additional articles and texts were identified from reference lists.

2.2 International trends on ageing

Many international organisations, such as the United Nations (UN), the Organisation for Economic Development (OECD) and the World Health Organisation (WHO), have studied the issue of the ageing population and developed concepts and objectives to enhance the lives of older people. The ‘healthy ageing’ concept is a relatively recent phenomenon and encompasses both the physical and psychological dimensions of the ageing person irrespective of physical conditions which may impair mobility or functional capacity (Hansen-Kyle, 2005; Strawbridge, Wallhagen, & Cohen, 2002; van Maanen, 2006). Healthy ageing is the amalgamation of resilience, physical and mental well-being, and preservation of independence with the ability to make choices about lifestyle and care needs (Gabriel & Bowling, 2004; Hansen-Kyle, 2005; Koch, et al., 2007; van Maanen, 2006). The promotion of healthy ageing is regarded as the counterpoint to reforming the funding for healthcare and disability services (Merlis, 2000). Encouraging a healthier, more independent, older population also aims to offset the potential impact of the growing numbers of older people on healthcare, disability and residential care costs. Such costs are generally paid for by public expenditure but the diminishing working-age population will mean a reduced tax take for such expenditure (Davis & Fabling, 2002). One of many positive initiatives emerging out of
the healthy ageing model comes in the form of programmes intent on improving muscle strength as a means of preserving physical mobility and independence in older people, a trend evident in New Zealand with positive results on the physical fitness of the older people involved (Peri, et al., 2007).

2.3 New Zealand Government policies on the ageing population

International trends that have been adopted by New Zealand policy makers include those strategies aimed at improving health and well-being for the ageing population while at the same time reducing potential demands on health care and disability support services in the future. The most notable government initiative is the New Zealand Positive Ageing Strategy (Dalziel, 2001). The Strategy places emphasis on community engagement and empowering lifestyle choices for older people while simultaneously fostering a positive attitude toward valuing their contribution to society. The document has provided a foundation for subsequent policies, one of which is the Health for Older People Strategy (Dyson, 2002). Initiated by the Ministry of Social Development (MSD) and utilising the life course perspective methodology, the policy focuses on encouraging informed choice, health and well-being, and the planning of services to meet the health and disability needs of an ageing population. Of importance is the idea of promoting healthy lifestyle choices at an earlier age thereby reducing disability and chronic illnesses as these people age. The strategy also places emphasis on older people “ageing in place” (p. 46). The concept of ‘ageing in place’ stems from the work of the OECD which promoted the notion that people should be able to live as long as possible in their own homes and community, and has become a crucial element of all policies in New Zealand related to the ageing population (Schofield, Davey, Keeling, & Parsons, 2006). The key constituents that define ageing in place are the ability to make choices, preserve independence and receive appropriate support as needed. There is acknowledgement that people want to continue living in their own homes for as long as possible and that they can expect to receive support from a variety of sources to maintain independence. Such sources of support combine unpaid and informal assistance, usually from family or friends, and paid formal services, generally resourced by District Health Boards (DHB) and funded through the Disability Support Services (DSS) (Schofield, et al., 2006).

In recognition of the predicted increase in numbers of older people in New Zealand, successive governments have consulted with experts in the field to determine a plan for coping with the potential ageing needs of this older cohort resulting in the development of an array of policies.
2.3.1 Current policies and funding for older peoples’ support services

The OECD has published documents on issues surrounding the increasing numbers of people aged over 65 and the impact this will have on the workforce, health costs and lifestyles of the population (Oxley, 2009). Among the recommendations is a strong emphasis on active ageing with a more gradual retirement from paid employment, which together aim to reduce the anticipated cost of government superannuation, pensions, and health and disability support services.

Government policies
The New Zealand Positive Ageing Strategy provides a framework that emphasises the valuable resource and contribution older people provide to society (Dalziel, 2001). The intent of the strategy was to empower older people into making lifestyle choices and promote positive attitudes toward ageing. The document has provided a foundation for subsequent policies, such as the Health of Older People Strategy, with a focus on how the strategies will be achieved and how the services required will be funded to meet the stated objectives.

The Health for Older People Strategy aims to provide the nation with a vision and structure for the future of the ageing population in New Zealand (Dyson, 2002). Objectives centre on informed choice, health living, services planning and funding to meet disability needs, including family or whānau, and promoting “health and well-being in older age” (p. 1). By acknowledging the need to improve lifestyle choices for younger people the strategy aims to achieve better health for future older people with a reduced level of disability as they age than previous generations. However, the focal point of the strategy rests on the current older population, those aged 65 years and older, with an accent on living well and “ageing in place in the community” (p. 46). The MoH (2000) funds the healthcare sector, including the DHBs, which allocate funding for DSS, an arm of community sited services aimed at augmenting support for individual needs in order for older people to live independently. The scheme recognises the complexity of the health and disability support needs for older people and the importance of having access to services that are aligned to the specific needs of the individual. There is an expectation that the MoH and DHBs will work in close collaboration with older people and their families to provide health care and support services as required. However, it must be noted that the expenditure for long-term care of older people, at just under 0.5 percent Gross Domestic Profit (GDP), is the second lowest in the OECD with Australia at 1.8 percent GDP, and Sweden, the highest on the comparison table, at 2.75 percent GDP (OECD, 2005).
Government-funded health care services
For the 2010-2011 financial year, the New Zealand government funded healthcare was $12.738 billion, of which 79.2 percent was spent on DHB funding; 7.4 percent on health and disability services across all ages, and 1 percent on workforce training and development (Ministry of Health, 2011b). A new entry to the funding split for this period was the 1.4 percent directed to the Primary Health Care Strategy (PHCS) which funds a lower cost service at the community level in the form of Primary Health Organisations (PHOs). The health expenditure for 2010-2011 increased by $354 million from the 2009-2010 period, half of which can be attributed to the addition of the PHCS. This was an initiative of the Labour Government in which the development of PHOs made community-based medical and nursing services more affordable and limited the cost of prescription medicines (King, 2003). The aim of the strategy was to improve access to health care, thereby meeting the government’s priority for reducing health inequality for those living in lower socioeconomic circumstances. One population group targeted for these reduced costs was older people.

Ministry of Health targets for improving population health
The largest expenditure from the health budget is directed at the DHBs which provides some primary, plus all public secondary and tertiary level services. The MoH sets targets each year for healthcare providers. For the 2010-2011 year the targets of particular interest to mid-life adults and older people included improved access to elective surgery, shorter waiting lists for cancer treatment, a reduction in cigarette smoking, and better services for cardiovascular disease (CVD) and diabetes mellitus (DM) (Ministry of Health, 2011a). The MoH (2011b) annual report revealed good progress by the DHBs on meeting these goals with the exception of improvements in CVD and DM management. Both of these conditions and smoking are linked to high admission rates to public hospitals for emergency medical and nursing care, with smoking alone estimated to cost $1.9 billion per annum in health-related services. A complication of CVD and DM is the risk of a heart attack and stroke. The MoH stated these conditions are the leading cause of death in New Zealand. However, a consequence of stroke is the high rate of physical disabilities, and is regarded as the principal cause of disability in the New Zealand population (Stroke Foundation of New Zealand, (n. d.).

Accident Compensation Corporation funding for older people
New Zealand also meets the needs of accident victims through the Accident Compensation Corporation (ACC), a ‘no fault’ scheme providing cover for personal injury for New Zealand residents and international visitors funded through government, employer and employee
contributions (Accident Compensation Corporation, 2010). For older people who are at greater risk of impaired mobility and falls, ACC meets the cost of hospital admissions and surgery, and the supply of mobility and functional aids, and assistance with basic daily activities on discharge from hospital. However, the supply of such services is for a limited time and is dependent on on-going assessment of need. ACC recognises the high risk of injuries from falling in people aged 65 and older and has targeted funding to reduce the incidence of falls for this group through modified exercise programmes aimed at improving physical strength and balance (Street, 2008). To date, these measures have seen a greater than expected reduction of 5.1% as measured through hospital admission and discharge rates. An estimate of the cost to ACC for injury rehabilitation as a result of falls for people over 65 is approximately $60 million per annum (ACC, 2010).

Privately-funded healthcare
Not all people living in New Zealand rely solely on publically-funded health care services. Privately funded services have steadily increased over the ten year period from 1998 to 2008 accounting for approximately 19.8 percent of health care expenditure (Ministry of Health, 2010a). While some individuals have paid personally for their health services, those funded through medical insurance schemes have reduced in number over the same period of time from 6 percent of the population in 1998 to 4.9 percent in 2008. MoH statistics indicate that in 2008, there were 461,693 people in the Baby Boomer cohort covered by medical insurance; however, the data also suggested the number diminished with each subsequent five year age bracket from the age of 65 years. The reduced enrolment in medical insurance schemes may be due to the prohibitive cost for those on a retirement income as well as the obvious factor of the insured person’s demise. Private funding contributes to some of the home-based care for older people as well as to residential living costs. MoH data for the 2007-2008 year indicates 32% of spending was on community-based personal support. These figures would suggest that people are accessing support services to assist their functioning at home when either, they have not requested an assessment of need, or, do not meet the eligibility criteria for services.

Given the separate funding streams, there is a challenge to coordinating services to adequately meet the specific needs of the older person. One aspect of the Health for Older People Strategy that aims to improve collaboration relates to the Needs Assessment and Service Co-ordination Service (NASC) guidelines developed by the MoH to integrate assessment processes for all services (Dalziel, 2001). NASC is contracted to DSS and works with people with disabilities and their families to determine the type and level of
support they require to meet their needs (Ministry of Health, 2010b). The needs of people with disabilities can vary significantly with some people requiring only mobility aids and safety rails; for others the involvement of support workers is necessary to attend to their basic daily activities.

2.3.2 Future planning and direction

Eligibility for disability support services is based on individual needs, however, future planning and direction of services for older people is not entirely clear. While on-going research attempts to project the potential costs of health care and support services for an ageing population, the actual service requirements will only be realised at the time when the individual’s needs arise. The May 2011 government budget provided for extra funding to be spent on health-related services with an additional $130 million allocated for disability support services of which $32.5 million was allocated for the 2011-2012 financial year (Ministry of Health, 2011b). Part of the increased funding was to cover the estimated price rise of 1.5 percent across a wide range of services within the disability sector. The overall additional funds amounted to: $6.6 million (m) for home and community services, $0.84m for respite services to provide relief for caregivers of a disabled person, and $0.63m for care worker support. The latter support service is intended to ease the burden of duties for the caregiver. It is also intended that these services have been put in place to meet the needs of people with disabilities regardless of age. Given the projected increase in the number of people aged 65 years and older, the funding for services targeted at ensuring they are able to ‘age in place’ is doubtful and may not be sufficient to meet their continuing needs.

2.4. Quality of life and the factors that impact on ageing

Ageing is a complex, multi-faceted phenomenon which all people are forced to face as they grow older. The complexity of this process combines life events, physical and mental health, socio-economic circumstances, attitudes to ageing, and personal characteristics (Koch, et al., 2007). The rating of quality of life is subjective and may vary with the individual’s current situation (Gabriel & Bowling, 2004). It is also dependent on conditions beyond the individual sphere of control, such as accidents or medical events resulting in disability, unemployment, and changed economic circumstances and housing (Kahn & Juster, 2002). The sense of satisfaction a person has with their life is dependent on these factors and is where the link between physical, psychological and social functioning has implications for older people (Antonucci, et al., 2002). Hansen-Kyle (2005) noted that there are diminished levels of life
satisfaction among older women and those with reduced independence and also among those who are lonely. To gain a clearer understanding of these complex issues it is necessary to consider the separate factors that contribute to the overall sense of well-being of the older person.

2.4.1 Health, Illness and Disability

Life expectancy for the “young-old”, (those aged between 65 and 84) has increased as a consequence of better health while the “old-old”, those aged 85 and older, tend to be more physically and psychologically frail and dependent on support in the community or residential care facilities (Barrett, 2006, p. 115). The incidence of increasing disability and chronic illnesses for older people was evident in a study in the United Kingdom (UK) which demonstrated a steady rise in the need to access community-based services, such as General Practitioners, District Nurses, Home Help organisations and Day Centres (Boniface & Denham, 1997). A negative correlation between well-being and life satisfaction for people aged over 80 and the accumulation of co-morbidities, functional impairment and social loss was also evident in the older population (Antonucci, et al., 2002; Borg, et al., 2006). Such findings suggest that the gradual loss of physical prowess associated with ageing may significantly impact on an individual’s capacity to function or engage in the type of daily activities that assist in the maintenance of an independent lifestyle, such as bathing, dressing, cooking or exercise.

In New Zealand, Māori and Pacific peoples are expected to experience a greater ill-health attributed to diet and lifestyle with an increase in associated chronic conditions and disability than their European and Asian counterparts (Cox & Hope, 2006). A study commissioned by OECD considered functional health status among older people with disability or loss of function has been identified as of major concern for the increasing numbers of people living in industrialised countries (Jacobzone, 2000). A comparison of data from Australia, Canada, France, Germany, Japan, Sweden, UK, and the United States of America (USA) revealed increasing trends in disability among those aged 75 years and older across all countries. The report noted that while admission to residential care facilities had decreased over the years studied (1975-1995), the over 80 year old group continued to require a level of support not adequately met by provisions in the community.
**Healthy Ageing**

A variety of concepts have been developed that draw attention to the specific issues of ageing and health. Two such concepts are ‘healthy ageing’; the maintenance of physical and psychological health, and ‘successful ageing’; a broader term which encompasses self-satisfaction and a sense of fulfilment with life irrespective of the presence of any physical disability or chronic illness (Hansen-Kyle, 2005; Strawbridge, et al., 2002; van Maanen, 2006). The concept of healthy ageing includes the physical and psychological processes associated with growing older, and not merely the absence of chronic illness or disability (Hansen-Kyle, 2005). Older people may still regard themselves as having very fulfilling lives within the limitations posed by significant medical conditions and disabilities (van Maanen, 2006). Research exploring older people’s views on well-being and successful ageing found that the presence of chronic illness did not necessarily correlate to dissatisfaction with ageing, just as physical and cognitive health did not equate with ageing successfully (Strawbridge, et al., 2002). The results contrasted with the health professionals’ views that assumed successful ageing was defined by the absence of illness or disability.

**Life satisfaction and resilience**

Self-reported levels of life-satisfaction or well-being are also important and potentially reflect the older person’s ability to adapt to age-related changes (Kahn & Juster, 2002). Adaptability or resilience has been recognised as an important factor in understanding how older people meet the challenges of ageing (Antonucci et al., 2002; Hansen-Kyle, 2005; Kahn & Juster, 2002). Resilience can best be described as the individual’s ability to adapt and succeed when faced with physical changes, chronic illness, and loss, such as the death of a partner or retirement from active employment (Blieszner, 2007; Hardy, Concato, & Gill, 2004; Nygren, et al., 2005). In a study of older men and women known to have high levels of resilience levels, concepts of feeling connected, independence, and meaning were identified, which together defined positive ageing (Aléx, 2010). Reduction in the level of resilience may result from mental depression secondary to physical disability which can be a significant factor for the older old person (Lenze, et al., 2001; Mehta, et al., 2008; Pennix, Deeg, van Eijk, Beekman, & Guralnik, 2000).

Clearly purpose in life and well-being are influential forces in the way in which the older person copes with ageing. The quality of health is also significant to an individual’s sense of well-being and contributes to their stamina when confronting adversity (Gillis & Perry, 1991; Jacobzone, 2000; Kee, 2003).
**Ageing and frailty**

While many health professionals associate physiological loss with frailty the “trajectory of frailty is unique for each individual” and as such frailty should be regarded as a continuum rather than a defined state (Markle-Reid & Browne, 2003, p. 65). The notion of a continuum acknowledges varying degrees of frailty as the person's health status fluctuates with illness and recovery. Understanding the concept of frailty requires insight into the complexity of the relationship between physical changes and social and contextual factors (Barrett, 2006).

Nygren, et al. (2005) dismissed the myth that increasing age equates to increasing frailty instead noting that a sense of purpose in life was being instrumental in overcoming age-related physical and mental health changes. While some physical deterioration is inherent in natural ageing, Merlis (2000) regarded the real challenge lay in promoting healthy ageing and prevention of chronic conditions and disability rather than restructuring funding and care delivery.

**Musculoskeletal changes and disability**

Musculoskeletal changes have been noted as the most common area of disability among older people, with arthritis and joint impairment considered the foremost contributor to loss of independence and functional capacity (Gignac, Cott, & Badley, 2000; Hughes, Dunlop, Edelman, Chang & Singer, 1994). Baseline joint deterioration is a clear predictor of future disability; greater than any other physical or psychological condition (Hughes, et al., 1994). Older women were more likely than men to report some degree of disability, especially those associated with osteoporosis, osteoarthritis and back problems (Naumann Murtagh & Hubert, 2004). The limitations imposed by musculoskeletal impairment, particularly osteoarthritis, and its associated pain were major indicators for the increasing need for functional support for older people. For those living with muscular-skeletal changes, the key factor for maintaining independence was the treatment of pain (Kee, 2003). Given the greater longevity of women in western societies and the evidence of increasing joint dysfunction associated with ageing, there are clear implications for the provision of symptom management and functional support for the burgeoning older population.

**Programmed exercise to promote physical independence**

A variety of programmes have been instituted aimed at promoting greater muscle strength, reducing immobility and fostering physical independence (Capodaglio, et al., 2005; Kee, 2003; Rejeski, et al., 2008; Peri et al., 2007; Scaf-Klomp, van Sonderen, Sanderman, Ormel, & Kempen, 2001). In New Zealand, a controlled trial of an exercise programme aimed at
promoting functional capacity for residents in residential care was undertaken with results suggesting that such interventions have the potential to increase the physical performance of older people (Peri, et al., 2007). Peri, et al. (2007) confirm the findings of previous studies on the positive effects of a defined exercise programme which not only improved physical strength, mobility and functioning but also developed a more positive sense of well-being in the older participants (Capodaglio, et al., 2005; Dungan, Brown, & Ramsey, 1996).

2.4.2 Financial Factors

Financial status was also identified by Hansen-Kyle (2005) as a factor contributing to successful ageing with research participants indicating money problems impacted negatively on their sense of well-being as they aged. Like most Western countries, New Zealand has retirement or age-related benefit schemes to support the income of older people (Burns, Keswell, & Leibbrandt, 2005; Schieber, & Shoven, 2001). Residents are eligible for government funded superannuation from the age of 65 with the benefit, as at 2010, being $19,425.00 per annum before tax for an individual living alone and $29,184.00 for a couple (Work & Income, 2010). In addition, healthcare and disability costs are supplemented through government funding of DHBs for hospital and specialist services and disability support, and PHOs for community healthcare services (Ministry of Health, 2010a). It is uncertain, however, whether age related pensions will continue to meet the monetary needs of older people, even in a society where healthcare is publicly funded.

Financial provision for retirement

New Zealand’s pension and health care funding is similar to that of the UK where concerns are now being expressed regarding future planning for the expected increase in the numbers of older people in the population (Falkingham & Grundy, 2006; Schieber, & Shoven, 2001). Disquiet is arising amongst pre-retirement workers regarding the adequacy of planning for future needs and the implications of poor investment decisions coupled with the potential effect of the growing numbers of older people claiming pensions from the government (Lee & Skinner, 1999; Schieber & Shoven, 2001). While many older people may have made provision for their retirement years through savings and investments, the recent global financial crisis has clearly impacted on the value of these assets. Of particular note is the decline in property values and failure of several finance companies (Diplock, 2009). The failure of investments companies, such as Blue Chip, Hanover, Bridgecorp and Lombard are notable examples of the impact of the global economy resulting in significant financial loss for investors (Gawith, 2010; Phare, 2009). More fortunate investors, while receiving minimal
interest returns on their bank deposit savings, have been comforted by the government guaranteed scheme aimed at ensuring stability in the banking sector and protecting investors’ assets (Diplock, 2009; Key, 2008).

Another factor affecting potential income in old age is employment-related superannuation schemes and the length of employment record across the working life. In the UK the workforce experiences of men and women differ; men generally have a higher level of engagement in paid employment over their adult life and there is also a financial discrepancy between genders (linked to their earning capacity) in pension payments (Falkingham & Grundy, 2006). The Australian female Baby Boomer cohort began working before the compulsory superannuation scheme was introduced in 1992 and with variable employment patterns related to child rearing these women are likely to have lower levels of savings from the scheme (Jefferson & Preston, 2007). New Zealand also introduced a compulsory superannuation savings scheme in 1974 which was subsequently abolished in 1975 following a change in government. Had the scheme remained in place it would have elevated the New Zealand financial system to that of a “potential Switzerland of the Antipodes”; with a projected gross domestic growth of 146 percent, compared to 82 percent for the current Australian model (Gaynor, 2007). The resulting reserves would have seen a mere 2 percent being withdrawn annually to furnish current retirement pensions. The consequences of this political decision have affected the financial prosperity of the country, including funding for future health and disability support services and age-related benefits.

Increasing divorce rates, especially among women in countries like New Zealand, Australia, the USA and UK is another factor which may impact on the retirement income of older women. In the USA, 97 percent of all older people receive a regular income from social security benefits; retired workers’ payments are based on a life time of contributions with women’s benefits closely related to those of their husband (Harrington Meyer, Wolf, & Himes, 2005). For American women benefits received are linked to duration of marriage meaning broken patterns of employment and divorce may result in significant financial disadvantage.

Poverty in old age

Women are particularly at risk of “pensioner poverty” as a result of less personal income compounded by greater longevity; this means that any resources they may have accrued at the beginning of their retirement years will have diminished considerably over the lengthy period of their life (Falkingham & Grundy, 2006, p.16). Financial inadequacy makes women
more vulnerable to ill-health through limited access to self-funded healthcare and social services; factors evident in countries with less well developed government-funded support structures (Gorman & Heslop, 2002). Many older women have “a lifetime of multiple and interconnected disadvantages” beginning with financial hardship as a child leading to limited educational and employment prospects and ultimately to heavy reliance on government funded pensions and social services (Gunnarsson, 2002, p. 713). The vulnerable life-course that some people experience, including divorce and lower rates of home ownership, has the potential to impact on the financial resources for future older people (Jefferson & Preston, 2007; Solomou, Richards, Huppert, Brayne, & Morgan, 1998). Many of the current female Baby Boomers are struggling to save for their retirement while simultaneously adjusting their employment to accommodate the needs of their children and possibly ageing parents. An OECD report on poverty across 44 countries revealed that only 11 percent of older people in New Zealand received employer-provided superannuation compared to 27 percent in Australia and 49 percent in the UK, while almost 100 percent of older New Zealanders’ received a government funded pension (Whitehouse, 2000). The current pension provides the financial support that is necessary for the many older people who, through personal choice or inability, have not accumulated assets to fund their retirement.

Unfortunately, government-funded superannuation does not cover the high cost of current rental housing prevalent in many urban areas meaning the provision of government housing is essential to meet residential needs of many older people (Thorns, 2000). For those who own a home, the same housing maintenance costs are incurred whether the older person lives alone or with a spouse or partner. Clearly, having a financial buffer, such as private superannuation, investments, or a rental property, as a means of generating additional income will enable the older person maintain a reasonable life style, or to at least have the ability to fund their health and disability needs.

Financial preparedness for retirement
Three key elements to financial security in retirement have been identified; social security benefits, pensions, and savings (Fisher, 2007a). However, it is apparent there is considerable variation in the financial preparedness for retirement and ageing needs amongst the Baby Boomer population with many people unable to pay their current living expenses let alone save for retirement (Cutler, 1998). Individuals or couples with children spent more on living and health care costs and less on future planning through pension contributions, savings and insurance. A trend has emerged in the USA for people to
continuing working part-time after their official retirement age, possibly to supplement pension payments (Fisher, 2007b; Mergenhagan, 1996).

Concern has been expressed regarding the likely projected costs of an ageing population and the potential implications for government-funded healthcare (Dang, Antolin, & Oxley, 2001; Parker & Clarke, 1997). Greater individual or family responsibility was acknowledged nevertheless expectations remain high for state-funding for pensions and aged-care costs (Deeming & Keen, 2002; Parker & Clarke, 1997; Wenger, 1999). As a consequence of the need to prepare for their own future ageing increasing numbers of mid-life women are in the workforce, effectively reducing their capacity to care for older parents or other relatives; a situation with implications for public-funded aged-care resources.

Social policies that place expectations on the population to save for, or insure against, healthcare needs in old age are unrealistic for people experiencing a life time of low income. In the UK, 50 percent of those approaching 65 years of age experience financial difficulties and 60 percent of older people relied on the informal care provided by family and friends (Deeming & Keen, 2002). There was no prediction as to whether future older people could expect the same level of support from their children or grandchildren.

While the financial factors associated with the ageing Baby Boomer cohort are of concern, Stearns and Norton (2004) questioned whether projections of expenditure on aged care may have been overestimated. They suggested that while this population group was expected to have a greater life expectancy, they were also more conscious of aiming for a healthy lifestyle and taking advantage of new technologies to delay disability. Maintaining health and reducing disability has the potential to limit the period of time toward the end of life when healthcare costs are known to be the greatest thereby reducing rather than alleviating government expenditure on aged-related care. Not all aged-care services in New Zealand are government-funded with means testing applied to some services, such as private hospital level and rest home care, home care in the form of housework and meal preparation, and home alternations (Ashton, 2000).

Two common threads are apparent: Older people living alone can be financially and socially disadvantaged, and there are variations in the capacity of adult children to provide functional support to their ageing parents.
2.4.3 Independence and community-based support

Older people tend to regard their home as a refuge which makes housing an important consideration in maintaining a reasonable quality of life and preserving independence (Borg, et al., 2006; Davey, 2006). Social relationships and community participation also contribute to life satisfaction for many older people (Gabriel & Bowling, 2004). There is a strong relationship between the provision of government-funded community services, formal and informal support, and social connections to ensuring older people continue living safely in their homes.

Comparisons between older people of English and Asian-Indian ethnicity living in the UK revealed an attitude of expectation and reliance on the government for support services, regardless of family availability to provide support (Chih, 2006). The availability of functional support provided by family and friends is crucial to sustaining older people’s independence in the home; however, such support can be variable in a country such as New Zealand with high internal migration (Keeling, 2001, Statistics New Zealand, 2010a). New Zealand has similar trends to Australia for internal migration with mid-life adults tending to change residence and locality in response to altered household configurations and employment opportunities; factors that will affect the social network of family support as they age (Statistics New Zealand, 2010b; Wulff, Champion, & Lobo, 2009). The outcome for such population mobility is the potential for their older parents to be living in a different locality from that of their family support. Relationships involving separation by physical distance limit the opportunity for family members to provide functional support to older relatives necessitating the development of proxy or substitute support, often from grandchildren or from the neighbours of the older person (Keeling, 2001).

In their District Strategic Plan for 2006-2010, the Auckland District Health Board (ADHB) identified the need for increased services to support older people living safely and independently in the community (ADHB, 2006). It is recognised that many older people prefer to continue living in their own home well into their later years even when they are considered to be quite frail and dependent upon an increasing amount of support to meet their daily functional needs (Boniface & Denham, 1997; Bromley & Blieszner, 1997; Cheek, Ballantyne, Byers, & Quan, 2006; Jörgensen, 2007; Thémessl-Huber, Hubbard, & Munro, 2007; Vladek, 2005).
**Need for support services**

Previous research has established a clear link between living alone and the need for increased services to support this independence and reduce admission to residential care, including home visits by healthcare workers (Boniface & Denham, 1997; Elkan, et al., 2001; Hays, 2002). Older people living alone in the community are more inclined to seek healthcare services, are at greater threat of physical and psychological decline, and ultimately more likely to require admission to residential care (Backman & Hentinen, 1999; Boniface & Denham, 1997; Cheek, et al., 2006; Hays, 2002; Keeling, 2001). The literature is contradictory on older people seeking and receiving support in the home, nevertheless the availability of community support services from General Practitioners and District Nurses, functional support in the home, and access to Day Centres all contribute to the on-going wellbeing of the older person (Boniface & Denham, 1997; Hays, 2002). Day Centre services provide social and rehabilitation programmes aimed at improving functional capacity and competence in daily life which contribute to users’ physical and mental health, and functionality (Andersson Svidén, Tham & Borell, 2004; Irvin, Massey & Dorsey, 1997; Kuzya, et al., 2006).

Improved life style and advances in medical care means people are living longer and for women, in particular, living alone, with census figures revealing that four-fifths of women aged 85 and older were widowed (Khawaja & Thomson, 2000). As the older person becomes more physically or cognitively frail and the support services available fail to meet their needs, the outcome can be admission to residential care (Backman & Hentinen, 1999; Hays, 2002; Ng, Lee, & Chi, 2004). A New Zealand study found that difficulties in managing normal daily activities coupled with adult children living in another location were some of the significant risk factors leading older people to opt for entry to residential care (Jörgensen, 2007).

**Social interaction and life satisfaction**

Social engagement outside the home and participation in social networks provides a protective element in maintaining the health and independence of older people and has also been instrumental in improving morale and lowering rates of loneliness and depression (Elkan, et al, 2001; Elovainio & Kivimaki, 2000; Wenger, 1997). However, social and family relationships appear to have a more beneficial effect on women than men, including reassurance of self-worth, mental well-being and lowering the rate of mortality (Hays, 2002; Lyrya & Heikkinnen, 2006; Solomou, et al., 1998). For men, the social disconnection of divorce leads to a reduction in their sense of satisfaction with life (Solomou, et al, 1998). For
older people living alone, participation in Day Centres activities can be beneficial by alleviating the psychological effects of chronicity, preventing of loss of skills, reducing loneliness through social contact, and improving the overall sense of well-being (Dungan, et al., 1996; Tse & Howie, 2005).

Mutual support from a spouse or partner can contribute to the older person’s ability to maintain a level of independence in the community (Gignac, et al., 2000; Nihtilä & Martikainen, 2008; Quine, Morrell, & Kendig, 2008). Among the many challenges of growing old in a marital or similar relationship is coping with the consequences of physical or cognitive changes whereby the relationship may change from that of partner to caregiver or care recipient (Blieszner, 2007). New Zealand, like many other Western nations, promotes an attitude of individual self-reliance as evident in government policies on ageing and community residence of older people. For many older people living independently will require some level of formal or informal support to meet the needs associated with ageing and daily living.

**Family relationships and co-residence**

Family relationships and feeling cared for are important to the older person and their sense of well-being, and having younger family members to offer functional support eases the challenges of ageing (Piercy & Chapman, 2001; Strawbridge, et al., 2002). Reciprocity, including the sharing of income, between family members has been identified as an important factor in managing the structure and functioning of multi-generational households (Gorman & Heslop, 2002). A traditional family pattern for some older Asian parents is to rotate their residence between adult children (Ng, et al., 2004). While multi-generational households are not uncommon in countries such as Italy, Spain and parts of Asia and South America, older inhabitants of many western countries tend to retain quite separate housing (Blackman, 2000; Comas-Herrera, et al., 2006; Falkingham & Grundy, 2006; Miller, 1998; Pruchno, Burant, & Peters, 1997). Perhaps one reason for less co-residence is the generational differences in attitude and behaviour that can lead to tension amongst family members (Chih, 2006; Fairhurst, 2003). Currently there are no published data for the rates of multi-generational households in New Zealand. The Abbeyfield Trust, a charitable organisation, has eleven houses across the country providing co-residence living for financially disadvantaged older people; quite clearly insufficient for the many older people who might find such housing a positive solution to their needs (Abbeyfield New Zealand, 2010).
2.5 Intergenerational influences and values in caring for older relatives

Life course theory provides a dynamic perspective across the lifespan and relates to the concept of intergenerational influences and values. Maintaining continuity in the face of change is intrinsic to the ties that bind relatives together (Bengtson, Giarusso, Mabry, & Silverstein, 2002). Early childhood experiences within the family and the values instilled by previous generations determine the quality of the parent-child relationship and potential for future caring (Ingersoll-Dayton, Neal, & Hammer, 2001; Piercy, 2007; Piercy & Chapman, 2001; Pruchno, et al., 1997; Rook & Ituarte, 1999; Willson, Shuey, & Elder, 2003). A key element of intergenerational relationships is that they are both developmental and historical with individuals and families forming strategies to secure future supports for old age (Hareven, 2000, Petrie, 2006).

The sense of filial responsibility can be both functional and emotional with an emphasis on the social context from which potential support may emerge (Maugans, 1994; Petrie, 2006; Stein, et al., 1998). A study of New Zealand families of Chinese and European ethnicity suggested that filial obligation is part of the “family mosaic”, with evidence that helping younger family members set an example for them to reciprocate when the older adult ages (Ng, Loong, Liu, & Weatherall, 2000).

As the older person ages and is confronted by widowhood or divorce, the role of supporter tends to be taken up by their adult children (Spillman & Pezzin, 2000). The family structure and member participation style, coupled with a history of supporting one another, is significant in determining whether older people can expect their younger relatives to assist them as they age (de Jong Gierveld & Havens, 2004; Matthews & Tarler Rosner, 1988). Family relationships, the bonds of affection and on-going social contact are the primary factors that determine the closeness of intergenerational relationships and are linked to the willingness of adults to provide support to their older relatives (Beach, 1997; Cooney, 2000; Even-Zohar & Sarlin, 2009; Grundy & Henretta, 2006; Maugans, 1994). There is a strong argument that social contact with family is the critical element in maintaining the health and well-being of older people (Arber, Price, Davidson, & Perren, 2003a).
2.5.1 Reciprocity within family relationships

Increased longevity means there may be more generations alive than ever before with implications for both receiving and giving support (Maugans, 1994). The act of reciprocity is based on the quality of the relationship and emotional support, and the sense of equity between family members (Ingersoll-Dayton, et al., 2001; Walker, Pratt, & Oppy, 1992). The relationship between child and parent develop as the child transitions into adulthood but reciprocity relies on the connections at the core of family bonds (Cooney, 2000).

While reciprocity is clearly initiated by parents with the potential of developing such traits in the child, it may also be evident between the older person and their grandchildren (Tinker, 2002). Past experiences and present influences underlie the importance of the link between reciprocity and family relationship (Petrie, 2006; Whitbeck, Hoyt, & Huck, 1994). Two factors are liable to affect the degree and nature of intergenerational reciprocity; the chronological age of the generations, and the physical and psychological deterioration of the older person.

Since the end of World War II there has been a greater prevalence of three or four generation families and an increase in individual roles and responsibilities (Grundy & Henretta, 2006; Maugans, 1994; Ng, et al., 2000). Reciprocating care among relatives has been challenging with the wider age composition of the family often resulting in an increased risk of stress for the caregiver (Maugans, 1994; McKee, et al., 1999).

The exchange of services, such as financial contributions and caring for the grandchildren can be advantages of intergenerational support (Miller, 1998). Unfortunately, there are disadvantages too; these are generally centred on the adult child trying to meet the expectations of the older and younger family members and the stress of their parent’s interference in child rearing (Ingersoll-Dayton, et al., 2001; Miller, 1998). The ethos of reciprocity is well supported by older people as is filial responsibility and the duty of adult children toward their older parents.

2.5.2 Caring for older relatives

While still living independently older people appreciated emotional and functional support and influences on health and self-care practices from family members (Rook & Ituarte, 1999). Caregiving can be considered to be a family legacy with observation of parents’ caring for grandparents being powerful in shaping the ideas of younger family members (Piercy & Chapman, 2001). Research on intergenerational caring has identified the
development of an apprenticeship model of family caring (Piercy, 1998; Piercy, 2007; Piercy & Chapman, 2001). The carer relationship can provide a meaningful role within the family for grandchildren who may also benefit from their grandparents’ presence and wisdom (Miller, 1996; Wall & Spira, 2006). Supporting their grandparents increases grandchildren’s understanding and compassion for the older person, creating closer family bonds (Beach, 1997).

Variations in responsibility for care of older relatives have been observed between the family orientated systems of Ireland, Italy and Greece and the more individualistic preferences of Denmark, Norway and Sweden (Blackman, 2000). These differences extend from the more religious, cultural and filial expectations of the former countries to greater extent of welfare provision for older people in the UK and Scandinavia. Again the links between intergenerational caring and involvement in the wider family structure affirms the primacy of the family as a social unit with members supporting each other (Blackman, 2000; Piercy & Chapman, 2001). Similarly, the Spanish value family interdependence with emotional support from adult children and co-residence with family being key factors in maintaining the physical and mental well-being of older people (Zunzunegui, Béland, & Otero, 2001).

Research in New Zealand on people of Chinese and European ethnicities indicated that both groups felt a strong positive obligation of respect for and social contact with older relatives (Ng, et al., 2000). The sense of filial responsibility for older relatives is complex and peculiar to individual families as well as to ethnic groupings but a health crisis for the older person is the most likely factor to instigate the adult child to provide care or support for their parents (Bromley & Blieszner, 1997; Petrie, 2006). While being instrumental in influencing the health care decisions for their parents, younger people also experience considerable pressure from the obligation to care for their ageing relatives (Miller, 1998; Walker, Pratt, & Eddy, 1995).

The emotional attachment and reciprocated feelings were linked to a strong commitment to care with women the most probable and committed family member to support the older person (Piercy, 2007; Spillman & Pezzin, 2000). However, there was apparent ambivalence toward involvement in the care of parents-in-law or an older person with dementia, and the extent of support offered was influenced by the caregiver’s partner (McKee, et al., 1999; Maugans, 1994; Piercy & Chapman, 2001; Willson, et al., 2003). Societal changes have meant that women, the most frequent caregivers of older parents, are more likely to have multiple roles from spouse, to mother, and employee (O’Rand & Henretta, 1999).
2.5.3 Competing demands of the Sandwich generation

The Baby Boomers are also known as the ‘sandwich generation’; a term arising in the early 1990s to describe the impact of being caught between the older and younger generations. Situated between two generations of relatives, the Baby Boomers are faced with supporting their older relatives while simultaneously meeting the needs of their children (Petrie, 2006). Even the oldest of the cohort, at the age of 65, quite possibly have parents or other ageing relatives, in their eighth or ninth decade of life, who look to their younger relatives for support. These mid-life adults are also known as the “pivot generation”; being in the crucial position of providing various forms of support to the preceding and following generations (Grundy & Henretta, 2006, p. 709).

Daughters are twice to three times more likely to assume the carer role as sons but with increasing numbers of women in paid employment, the demands on their time to fulfil the dual roles of partner, parent and employee are challenged by the additional needs of an ageing parent (Lee, 1999; Spillman & Pezzin, 2000). Assumptions made about women’s innate caring capacity reflect societal ideology and expectations, and their lower social and economic power (Lee, 1999). The decreased fertility rate of the Baby Boomer generation will mean potentially fewer children in the future to support their ageing parents (Spillman & Pezzin, 2000). With only one or two siblings to provide assistance to their parents, it may necessitate grandchildren assuming a secondary carer role to ease their parents’ burden (Beach, 1997; Even-Zohar & Sharlin, 2009).

Conflict can arise between expectations and obligations resulting in stress and tension for adult children when they become caregivers to their parents (Wall & Spira, 2006). Some women fear that their partners and children would feel neglected when they take on the caregiver role for ageing parents and therefore tend to ignore their own needs in preference to sustaining the needs of the broader family (Wall & Spira, 2006). There are implications for the provision of future support for an ageing population as the demands and expectations on the family cause stress and a sense of burden.
2.6 Stress and burden associated with caring for older relatives

The significant stress and burden experienced by caregivers of ageing relatives arises from the conflicting demands of multiple roles (Hareven, 2000; McKee, et al., 1999; Sebern, 2005; Spillman & Pezzin; 2000; Theide et al., 1999). There are many factors that have the potential to lessen or increase the stress and burden associated with caring for older relatives. Some of these factors include the level of support required, both formal and informal, to meet the older person’s needs; adult children’s relationships with their siblings; and concerns for the safety and security of the older person.

2.6.1 Level of support required to meet the older person’s needs

Although both men and women are involved in providing support to older people, the probability is higher for mid-life women who are already supporting their children (Grundy & Henretta, 2006). Providing assistance to the older person may be constrained by time allocation and can impact on the caregiver’s ability to remain in paid employment (Arksey & Glendinning, 2007). Despite these limitations there is a general acceptance by families to take on a caregiver role for their older relatives (Miller, 1998; Wolf & Soldo, 2009). Family-based caregiving is regarded as an irreplaceable component of the health care delivery system (O’Rand & Henretta, 1999).

Support for the older person may involve a combination of companionship, functional and financial assistance. The emotional connection and companionship nature of the relationship between generations will generally continue across the life span through regular contact (Keeling, 2001). When the older person’s independence is threatened by illness or loss of their spouse, the adult children are generally activated into providing more practical or functional support (Matthews & Tarler Rosner, 1988). Such practical assistance generally involves assistance with shopping, cleaning, house and garden maintenance, and transport to appointments. Providing help can begin on a casual basis but increases in frequency as the older person’s health and independence diminishes (Lee, 1999). Financial needs vary considerably depending on the individual’s life course and effects of factors, such as divorce, interrupted or low income employment, limited retirement savings and reliance on state welfare (Falkingham & Grundy, 2006; Gunnarsson, 2002; Ingersoll-Dayton, et al., 2001; Jefferson & Preston, 2007).
Literature Review

The older person may need to access more formal support to assist their everyday functioning. In New Zealand, such services are provided by the DHBs based on functional need and asset-testing (Ministry of Health, 2000). For many older people, expectations of government-funded support services are based on a sense of entitlement derived from an established welfare system and history of taxes paid over their working lives (Chih, 2006). Attendance at day care centres and home-based support for older people is known to reduce mortality rates and admission to hospital (Elkan, et al., 2001; Kuzya, et al., 2006; Lyyra & Heikkinen, 2006).

The onset of dependency by the older person can create an imbalance in family relationships; while some adult children cope well, others struggle with these competing demands. Formal supports may alleviate the burden on caregivers but also having siblings who can share the burden of care may resolve some of the associated burden and stress (Miller, 1998).

2.6.2 Sibling relationships and sharing care provision

Sibling relationships can be “complex and dynamic” but as adults, the roles of siblings and their life trajectories may diverge considerably resulting in differing views on commitment to family members and priorities in life (Bengtson, et al., 2002; Roff, Martin, Jennings, Parker, & Harmon, 2007). Inequities between siblings, regardless of gender, in the provision of support to ageing parents can result in frustration and anger (Ingersoll-Dayton, Neal, Ha, & Hammer, 2003). While the contribution made by siblings varies based on proximity and personal commitments, aggravation arises from the sense that some siblings do not support their parents’ needs as they should (Roff, et al., 2007). It is clear that close proximity of adult children to their parents increases the availability of potential support (Ingersoll-Dayton, et al., 2003; Keeling, 2001; Smith, 1998).

Tension between siblings may arise from the sense of inequity or criticism of support provided to older parents, which can have a negative impact on the quality of the sibling relationship (Ingersoll-Dayton, et al., 2003; Wall &Spira, 2006). Conflict between siblings is common and often related to past events, therefore working together in support of ageing parents relies on close family relationships and agreement on the type of support needed by the older person (Matthews & Tarler Rosner, 1988; Pruchno, et al., 1997). In instances where siblings openly discussed problems it was discovered that their anxiety often related to safety concerns for the older person (Edwards & Forster, 1999).
2.6.3 Safety risks for older people living alone

Older people living alone were perceived to be at greater risk of social isolation and depression, and this has been linked to the risk of abuse, unmet needs and poorer health outcomes (Hays, 2002; Wenger, 1997). Having family living nearby provided an increased support network as adult children tended to take over tasks if it was apparent that the older person was having difficulty coping with daily living activities (Wenger, 1997). Events, such as recurrent falls, endorse doubts about the older person’s ability to cope independently precipitating the need for increased support provision (Cheek, et al., 2006). Another problem linked to safety risks for the older person was the suitability of the home in which they lived with many older people resisting suggestions to relocate to a property more suited to their physical limitations (Askham, Nelson, Tinker, & Handcock, 2000). Lack of family support and reliance on limited social networks has resulted in social isolation and greater safety risks for the older person, factors that may increase rates of admission to residential care (Cheek, et al., 2006; Dellasega & Nolan, 1997; Wenger, 1997).

2.7 Factors influencing entry to residential care among older people

Provision of healthcare needs, personal security, companionship and freedom from concern about home maintenance were all factors identified as influencing older Australians to seek residential placement (Cheek, et al., 2006). Several factors present significant risk to the older person’s ability to continue living in their home, including difficulties experienced in managing daily activities, being alone for long periods, family living far away, and concerns about housing (Jörgensen, 2007). Whilst older people have a strong desire to retain their independence, they may also ignore or be unaware of any deterioration in their physical or mental well-being (Cheek, et al., 2006). The advent of an unavoidable health crisis or a general decline in the health of the older person often precipitated the discussion and decision-making regarding admission to residential care (Bromley & Blieszner, 1997).

Other factors determining the older person’s need for a higher level of care included the appropriateness of their housing and whether modifications could be made to accommodate the functional needs and equipment associated with increasing disability (Davey, 2006). The ability of the adult child caregiver to cope with the older person’s needs alongside their own family and work commitments was another factor influencing the decisions regarding residential care (Dellasega & Nolan, 1997; McKee, et al., 1999). Caregivers may initially cope but subsequently experience physical, psychological and emotional stress as the older
person’s needs increase and health deteriorates (Lee, 1999). While many caregivers’ felt sadness, guilt and failure at the decision to admit the older person into residential care, these feelings were countered by the increased sense of security the older person experienced once they had settled into the residential care community (Dellasega & Nolan, 1997; Kellett; 1999; Kingston, Bernard, Biggs & Nettleton, 2001).

2.8 The ageing Baby Boomer generation

As a single population cohort, the Baby Boomers continue to have a significant impact on the social and cultural aspects of life in Western countries, and are likely to experience ageing quite differently to previous generations (Biggs, Phillipson, Leach, & Money, 2007). Attitudes to consumption of goods, leisure and extending paid employment beyond the general retirement age are also expected to be reshaped by these people.

2.8.1 Social changes for Baby Boomers across the life span

The Baby Boomers have forged their path through life, making social changes and causing governments to shape policies to accommodate their expectations for education, healthcare, housing and employment (Biggs, et al., 2007). The social changes for these people have resulted from the on-going effects of the 1930s economic depression and the Second World War, combined with improved healthcare, greater control over fertility and more women committed to paid employment, especially after having children. The women’s movement, which strove for equality of career pathway and remuneration, is also expected to influence women’s choices and expectations in retirement (Longino, 2005). Many of these women have experienced later marriage, higher rates of divorce and longer periods of independent living than their mothers (Longino, 2005; Quine, & Carter, 2006). The majority of Baby Boomer women have worked outside the home for some, if not all, of their working lives and many have additional resources, particularly financial, to support their ageing years.

The Baby Boomers are also a generation who are keen on leisure activities and in fact have popularised the concept of a healthy lifestyle which combined with medical advances has the potential to lessen the impact on limited health resources (Longino, 2005). Increasing life expectancy, for both men and women, may potentiate a longer period of retirement than previous generations (Arber, Davidson, & Ginn, 2003b; Fairhurst, 2003; Pink, 2004). While retirement is not compulsory and working life may extend into more flexible, part-time
positions, the cohort is likely to be supporting children through tertiary education and providing supplementary care for grandchildren while both parents work (Brett, 1999).

In New Zealand, the age criteria for receiving the government-funded superannuation benefit was raised from 60 to 65 years in 2001; a policy change that affected the oldest Baby Boomers due to celebrate their 65th birthday in 2011 (Khawaja & Thomson, 2000). In a recent review of the retirement income policy, the Retirement Commissioner recommended a gradual increase in the eligibility age for superannuation to 67 years by the 2033 and means-testing retirees to limit access to those with limited financial resources (Harper, 2011). While the current Prime Minister was opposed to such a proposition, he acknowledged the governments concern regarding the burgeoning numbers of people aged over 65 (Harper, 2011).

2.8.2 Expectations of ageing Baby Boomers

Baby Boomers are depicted as more affluent than their parents’ generation due to high incomes, career development and greater financial well-being (Longino, 2005; Quine & Carter, 2006). However, Australian women of this age are less likely to be financially secure if they have focused more on family responsibilities and less on paid employment. Economic inequality within the cohort will be significant for the planners of aged care support services, especially for women who tend to have less financial resources and are likely to rely more on the government to provide for their aged-care needs (Evandrou & Falkingham, 2006). Although many 45-69 year old Australians have made provision for their future ageing financial needs approximately 50 percent of women and 30 percent of men expected to receive an old age pension, revealing a high expectation of government welfare (Quine & Carter, 2006).

While the literature has highlighted issues such as adequate financial planning for the post-retirement years, little has been published on the implications for families in taking responsibility for their older relatives.

2.8.3 Preferences in housing for the ageing Baby Boomers

Housing that meets the need for comfort, safety and convenience is linked to physical and psychological health and resilience in older people and makes an important contribution their overall sense of well-being (Davey, 2006). The choice and location of a home that meets the
Another important aspect of retaining independent living is adapting or renovating the existing dwelling to accommodate the physical mobility changes the older person may experience. Unsuitable housing for older people with disabilities is likely to reduce their level of independence, even precipitating the need to relocate into residential or assisted care facilities (Davey, 2006). For older people living in rental accommodation the situation is even worse because many landlords lack the incentives necessary to modify their property to suit the needs of those with disabilities.

Continual house maintenance, along with the desire for a change in lifestyle, social isolation, and changes to health and mobility were the four key factors identified in an Australian study on the influences on the older person’s choice to relocate to a retirement village (Stimson & McCrea, 2004). They also reported that the single most important indicator for such a move was social isolation, as many older people live alone following divorce or the death of their spouse. With the projected increase in retirees who are also living longer, the demand for services and facilities will necessitate expansion of the retirement village industry. However, such housing is costly and may be beyond the means of people in lower socioeconomic circumstances or of those who have always lived in rented accommodation (Wood, et al., 2011).

The aged-care facilities in New Zealand include approximately 318 rest homes, some with dementia level care; 336 rest homes inclusive of hospital level care; and 29 private hospitals (Ministry of Health, 2012). The Retirement Village Association (RVA) reported 277 member retirement villages and rest homes throughout the country, all located in urban areas (Retirement Village Association, 2011). While many of these facilities are scattered across all provinces and smaller cities, there is a greater presence in the three regions known to have an accumulation of retirees; Auckland, Tauranga and Christchurch. At present, it is impossible to know either what effect the recent Canterbury earthquakes have had on people’s choice of Christchurch as a retirement location, or the total damage sustained by both housing and residential care facilities. Some retirement village companies are demonstrating their awareness of the future demand on accommodation needs for older people by continuing to develop new facilities which cater for a range of people’s needs from independent villas, apartments and town houses through to hospital-level care. There are also the publically listed companies who, with a focus on meeting the expectations of
shareholders, are developing villages in some of the larger urban areas. One of these companies is Ryman Healthcare with 24 villages across the country (Ryman Healthcare, 2012). However, these businesses account for a very small number of the facilities detailed on the MoH website, indicating that many of the villages are independent, religiously affiliated, privately-owned, or choose not to be affiliated to the national organisation.

Retirement villages offer variable accommodation and services for older people, but the number of people demanding the village option for their retirement housing has increased (Grant, 2006). No doubt this increase is due to the growth in the ageing population, and given the demographic projections, demand is likely to continue. One of the positive aspects of village is the sense of community and social interaction created by living in close proximity to other retirees (Grant, 2006; Kingston, et al., 2001). The village environment fosters independent living while still providing for the individual support needs of the ageing residents.

While the Baby Boomer generation shows evidence of better health than their predecessors, and a determination to continue forging new pathways as they age, their preferences for future housing is largely unknown. Likewise the need for services to support the ageing population can only be extrapolated based on the trajectory of past generations and the projected numbers of those currently approaching older age.

2.8.4 Potential impact on aged care services

While much has been made of the improved health and lifestyle made popular by the Baby Boomer cohort, there is a suggestion that evidence of increasing rates of obesity, diabetes and cardiac conditions may lead to an increased reliance on healthcare services (Quine & Carter, 2006). Access to support services will become increasingly important as the older person ages, with greater potential to develop chronic ill health and associated disabilities (Pink, 2004; Whitehouse, 2000).

The Singaporean government has passed legislation making children legally responsible for care required by their ageing parents (Brett, 1999). Australia has also developed government policies placing emphasis on family responsibility in providing for older parents care needs by fostering greater intergenerational support alongside disincentives to rely on welfare benefits (Carter & Kerr, 2003). The New Zealand government has not ventured into such territory yet, but there are certainly concerns about the potential demands on
government funds for healthcare and age-related support services for the growing population of older people (Harper, 2011).

Transferring responsibility from the government to the family surmises a reduced commitment by the government to meet the needs of the projected ageing population. However, with many adult children in paid employment, having the financial burden of a student loan and home mortgage, and young children of their own, the ability to realise expectations of supporting ageing parents may be limited. If the family does not live in close proximity to the older person their ability to provide functional or practical assistance is negligible. Martin Hawes, a financial advisor, is quoted as having said that “the implications of saddling our children with high levels of debt before they have even started out in life is that we cannot expect any help from them in our old age” (as cited in Brett, 1999, p. 39). It is clear that a likely imbalance will develop between the working age population and the number of older people requiring services (Tinker, 2002). Such a disproportion will impact on the policies and funding linked to the support of older people as well as society in general.

With older people expecting the government to provide retirement pensions and aged care services and the government in turn looking to the younger family members, despite their work and family commitments, there appears to be a gulf in how older people are going to be supported as they age. Despite extensive research into many aspects of ageing for the Baby Boomer population, very little is known regarding their aspirations for their ageing needs (Quine & Carter, 2006). Clearly such issues, which affect the ageing cohort, their adult children and the government, warrants closer examination to determine the potential impact on aged-care services from both a fiscal and a workforce perspective.

Conclusion

It is evident from publications released by the UN, OECD and WHO that there is widespread recognition of concerns with regard to the impending increase in the number of older people and the implications this population growth will have on healthcare services and workforce, housing, and finances in the coming years. Many cultures have a sense of responsibility in the provision of care and support for older family members but in Western countries, particularly where the welfare system augments the services needed by the ageing population, families may be less inclined to become actively involved in caring for older people. The New Zealand government has already established policies aimed at encouraging healthy ageing and independence among the older population.
The factors impacting on quality of life such as health, illness and disability, finances and housing, and family relationships contribute to knowledge pertaining to the research topic. Despite an adult child’s willingness to assist their older parents, they may also be constrained by the competing demands of paid employment and their own, younger family members. Providing emotional and practical support to older relatives and even cohabitating is recognised as being the cause of considerable stress and tension within families. Relationships between caregivers and care recipients can be strained by the burden and relentlessness of the older person’s needs and expectations. Siblings may experience frustration as they seek equity in support provided to older parents. However, the intergenerational relationships and experiences of both providing and receiving care are not always negative. Reciprocity, loyalty and a positive attitude toward assisting the older person with their needs is evident in the literature.

The impending growth in the population of over 65 year old people in New Zealand is likely to impact on both workforce availability and funding for services to meet aged-related care needs. In recognition of these issues, the researcher considers that it is important to explore the recollected experiences and attitudes of current mid-life adults to caring for older people and how these experiences have influenced their expectations and planning for their own old age. The following chapter describes the theoretical foundation and methodology that provided the basis for the exploration of the factors outlined above.
Chapter 3

Life Course Perspective Theory

Life course perspective demands attention to aging and incorporates agency in the view that we construct our biographies through the decisions that we make and the paths that we take. (Connidis & Walker, 2009, p. 153)

Introduction

Theory and associated research methodology provide the foundation for any research project with the core theoretical concepts directing the study design. This project sought to define the issues through an exploratory process firstly with small groups and individuals, then with a larger group of the defined population. People experience, respond and perceive their reality and interactions differently which demands a theoretical perspective and research design that acknowledges such individuality. Recognising reality as “complex and diverse” requires acceptance of different types of knowledge to clarify the issue under investigation (Foss & Ellefsen, 2002, p. 246). Therefore, a qualitative approach was utilised to explore the phenomenon of interest from the perspective of the participants; acknowledging that individuals may vary considerably in their experiences and reflections of particular events (Polit, et al., 2001). Subsequently, further exploration of the topic from a quantitative perspective enabled the issues identified by individual participants to be put to a wider group of the target population. This chapter briefly outlines the researchers exploration of various theories and justification for the choice of the theory then discusses the Life Course Perspective theory and its relevance as the framework for the study.

3.1 Exploration of theoretical frameworks

Prior to determining an appropriate theory to guide the study the researcher studied the criteria for evaluating the adequacy of various theories. Fawcett (2005) provides a clear structure and explanation of factors that must be considered in the process of appraising the suitability of a theory in relation to the aims and intentions of the study to be undertaken. The criteria Fawcett uses to determine the adequacy of a theory to answer the research question include significance, consistency, clarity, testability, and empirical and pragmatic adequacy.
Each of these elements were considered during an extensive review of theories associated with ageing and caring for older people.

There are many relevant theories that could address the purpose of this study of the mid-life adult population. For example, *Engagement and Ageing* theory focuses on the current older population with particular attention to social interaction, commitment to civic life and supporting family and friends (Everard, Lach, Fisher & Baum, 2000; Hinterlong & Williamson, 2006-2007). Similarly, *Role Accumulation* theory considers human development and engagement with other that leads to social and emotional support, enhanced role status and gratification (Lee, 2007; Sieber, 1974). *Activity* theory provides a model for successful ageing with a focus of physical and mental health and transitioning into retirement (Schroots, 1996). *Modernisation and ageing* theory provides understanding of the nuclear family model and westernising of societies with consequential decline in family support and increased demands on public services linked to the sense of abandonment for older people (Aboderin, 2004; Gorman & Heslop, 2002). All of these theories attend to specific and important aspects of ageing and could have provided a sound basis for the objectives of this study. The rationale for choosing the *Life Course Perspective* theory was that it encompasses role development from childhood to old age; looking at the key stages across the life span, individual traits and factors which influence a person’s ability to cope with change, develop relationships, and their integration with society’s demands (Baltes, Freund, & Li, 2005; George, 1996; O’Rand, 2003).

### 3.2 Life Course Perspective Theory

Reflecting on the appropriateness of various theories it was decided that the Life Course Perspective theory provided a framework that best met Fawcett’s (2005) criteria in relation to the objectives of this study. Life course perspective theory presupposes that social circumstance and historical factors as well as family relationships influence the choices people make and their responses to the challenges presented throughout life (Hareven, 2000). The research undertaken here considers these elements are significant across the life span. The concepts of trajectory and transition contributing to the theory are clearly defined and consistent with changes people experience in life and roles developed and extinguished. The theory meets the criterion of testability in that data obtained can provide in-depth descriptions of personal experiences that can be linked to these theoretical concepts. Pragmatic adequacy addresses understanding of the theory and it’s application to the study, a factor demonstrated by the following discussion. The theory provides
Life Course Perspective Theory

understanding of how events or circumstances may impact on the lives of the current older people and their adult children, who may be supporting them, thus providing contextual understanding of how experiences shape expectations.

The theoretical model of life course perspective arose as a consequence of significant societal changes during the 20th century, such as the depression of the 1930’s, World War II, and post-war developments, the resulting increased birth rate and increasing prosperity, particularly in Western countries (Elder, 2007; George 1996; Hareven, 2000; McLanahan & Sorensen, 1985). The term ‘life course perspective’ has been used interchangeably with ‘life cycle’, ‘life history’ and ‘life span’ (Elder, 2007). However, the phrase life course perspective is particularly relevant to the study as it encompasses the chronological sequence of events, and the views and experiences of both individuals and age-cohorts. Life course theory comprises sociological concepts and incorporates both human development and historical conditions (Maugans, 1994). Thus the theory takes into consideration individuals’ roles which are influenced or driven by social contexts and events and the relevant historical influences. The contexts extend from the micro level of family and peer relationships to the macro level of state or government level policies. As Maugans (1994) states the theory “highlights the critical periods of individual and family development and in this way accounts for change in families over time” (p. 140). Factors such as the 1930’s depression, World War II, and increased participation of women in paid employment have influenced the lives of previous generations resulting in social change which has affected the childhood and attitudes of this study’s participants.

Influential in developing an understanding of the life course perspective theory American academic and researcher Glen Elder first wrote about the various elements of the theory such as the intertwining trajectories and role development across generations (Elder, 1985). Subsequently, he has continued to clarify the theory along with its application to research (Elder, 2007). There are many instances of other research projects which have applied the life course perspective theory as a basis for studying aspects of ageing. For example, Van Willigen (2000) compared the benefits of volunteering activities on young adults with those aged over 60 years determining greater life satisfaction and perceived health among the older participants. Her research utilised the life course perspective theory to provide context to the comparisons between distinct age groups. Whereas Moen, Robison and Dempster-McClain (1995) reinterviewed participants thirty years on from a 1959 study to develop an understanding of the factors that shape what women bring to the caregiving role and the resulting effect on their emotional health. Applying all concepts within the life course
Life Course Perspective Theory

perspective theory Evans, Coon and Ume (2011) studied the cultural and contextual factors and impact of burden for Mexican American caregivers of older relatives.

Life course perspective continues to frame studies aimed at understanding how medical conditions and lifestyle factors in childhood, adolescence and early adulthood influence the health of mid to later adults and older people (Ulrich Mayer, 2009). In fact, Ulrich Mayer considers “life course research as a field is still cumulative, progressive and innovative” for the purpose of studying the human condition (p.416). It has been asserted that research using life course perspective theory has engendered considerable debate on social structures and social change, and addressed social policy challenges (Heinz & Krüger, 2001). Intergenerational succession of relationships between parent and child is a distinctive feature of the theory, a factor crucial to the development of supportive and caring functions at various points in life (Allen, Blieszner, & Roberto, 2000; Bengtson, et al., 2002; Elder, 2007; Uhlenberg, 1996). It is this intrinsic relationship between parent and child that influences attitudes on ageing and also the nature of support networks and reciprocity that develop in response to perceived physical, functional, emotional and financial needs, and an area of interest in this study.

There are three main concepts which thread through the life course perspective theory; trajectory, transition, and turning point (Elder, 2007). The concept of trajectory shapes and explains social structures and expectations that influence the lives of individuals within society across the lifespan. Transition describes development and change occurring in response to maturation and major life events such as progression in roles from education to employment or assuming parenthood. The term turning point explains collective, but more particularly individual responses to a critical event that brings about a decisive change in behaviour or role, for example the death of a significant person, employment redundancy or relationship dissolution that can lead to major changes to an individual’s life. Turning point characterises a substantial alteration in direction that may be permanent or temporary depending on the precipitating event (Hutchison, 2011). Including turning point, which focus on the individual, would have resulted in considerable digression from the purpose of this study which was to learn how people encompass expanded roles, particularly caring for an older person, within the normal process of their life course. Therefore, the study focused on the concepts of trajectory and transition for the broader angle they provided on the study objectives and accordingly formed the key theoretical elements underpinning the study. The following section discusses the key areas of life-span expectations, relationships and family influences, recent historical and social changes in New Zealand. Also responses to change
are explored to provide a deeper understanding of the theory and concepts of trajectory and transition.

3.2.1 Life-span trajectories and role expectations

Trajectories take a long–term outlook with a focus on patterns of adjustment, constancy and continuity (Elder & Kirkpatrick Johnson, 2003; Hutchison, 2011). The life span trajectory will involve many role transitions and relationships that develop or discontinue making the life course very diverse. The notions of “norms and roles” prescribe not only the behaviour of individuals but also the connection between family members (Heinz & Kruger, 2001; Maugans, 1994, p. 143). It is the changes in norms that result in modification to roles, role expectations, life path and family reciprocity. Early life transitions can have considerable bearing on the subsequent passage through life. A child born in the 1920’s lived through the deprivations of the extensive economic depression of the 1930’s and stresses and possible grief associated with World War II. One assertion is that such events in early life exert “enduring influences on later life patterns” (George, 1993, p. 361), a view shared by Conndis and Walker (2009) who contend that the Great Depression severely limited women’s options in life to marriage and motherhood. Such major world events had the potential to significantly affect the direction of peoples’ lives including social and family relationships and economic well-being with a ripple on effect on subsequent generations. Many research projects have explored the effect of these events on participants’ life path and achievements. For example, Umberson, Williams, Powers, Chen and Campbell (2005) used the life course perspectives theory as a basis for their study of the development of trajectories on the decline of marital relationships over time. Similarly, Calvo and Sarkisian (2011) focused on transitions in their exploration of the impact on health, well-being and social ties as an outcome of managed or speedy retirement from paid employment.

Life span trajectories and transitions are shaped by institutional structures, such as education and career opportunities, and societal expectations such as marriage and parenthood, as well the individual’s aspirations (Heinz & Kruger, 2001). Trajectories and the meaning of life are also subjected to the influences of cultural principles and kinship relationships which can be forceful in determining the pathway an individual establishes (Lowestein, 2003). Experiences in childhood can have lasting effects that continue into adulthood and ageing of the individual, influencing both choices and options in life (Hutchison, 2011).
Life span trajectories and roles are intrinsically intertwined but understanding how these factors develop provides some explanation for how intergenerational caring, especially of older people occurs. Children of the depression and war years have gone on to become the parents of the Baby Boomers; the current mid-life adults whose anticipation of future ageing is the subject of this research. Now members of the older population, the Baby Boomers' parents have not only influenced their children's life trajectory but also their potential as caregivers through their own pattern of caring for older people.

3.2.2 Relationships and family influences

The development of the child's sense of self in an environment of parental influence, love and assurance, and the social setting which they reside ultimately results in an individual's character and identity (Cramer, 2000; Erikson, 1980). Family ideals and values are powerful in developing a child's sense of life trajectory with family relationships being crucial understanding the wider world (Akiyama, Antonucci, Takahashi, & Langfahl, 2003; Erikson, 1982; Hutchison, 2011). Whether the influences that shape the person are positive or negative, the outcome remains the same; that of a unique personality. Children develop within a complex arrangement of family connections that rely on the history of shared experiences and expectations (Laible & Thompson, 2007). Such significant relationships are dynamic and changeable as individuals and the people they interact with mature across the lifespan. It is well recognised that people are interdependent and cannot exist in isolation but are part of socially constructed groups and that these groups interact with one another; shaping individuality and enabling the establishment and maintenance of relationships (Hogg, 2006; Hutchison, 2011).

Interactions with other people and participation in different social environments are known to be influential in the development of the individual's thoughts, attitudes, actions and behaviours (George, 1996). Personal values and beliefs may remain closely linked to that of the person's parents or other people influential in their formative years. While many Baby Boomers were raised in a traditional two-parent family, changing social structures in Western society have challenged adherence to the long-established life trajectories and role transitions. Those born in the 1940s-1960s have different expectations with regard to education, employment, family development, and retirement than previous generations (Arber, et al., 2003a; Fairhurst, 2003; Hareven, 2000). It has been argued that parents who have followed a particular life pathway such as tertiary education, marriage, house acquisition and procreation will have, simply by evidence of their life structure, instilled the
same concept of life trajectory and transitions in their offspring (Akiyama, et al., 2003). However, whether the children go on to develop similar life patterns is dependent on social influences and relationships from outside the family or events which impact on the individual’s choices or view of life.

Adherence to traditional interpersonal relationships reinforces the “entrenched socially structured social relations of gender” (Connidis & Walker, 2009, p. 153). The authors, along with Kralik and van Loon (2008) argue that maintenance of such a social order; marriage, childbearing and rearing, and ties to family relationships ignores those not in the work force, such as women and older people, and confine their role in life to one of nurturing the family. For New Zealand women and their daughters the aftermath of World War II saw changing attitudes to marriage, motherhood and employment which set the scene for subsequent change to women’s roles in society (May, 1988). These social changes were supported to some extent by government policies developed in the 1950s which had a bearing on the domestic structure in New Zealand society; policies such as reduction in the value of the family benefit and practical support for full-time mothers, and acceptance of women as integral to the paid workforce (Nolan, 2002).

The changing composition of families, including later parenthood and blending of family groups with or without biological ties has led to relationships based more on voluntary choices than obligation (Allen, et al., 2000). It is apparent that the historical and social changes occurring prior to and during the early years of the Baby Boomer cohort have influenced family relationships and roles.

Conclusion

Theory provides the framework from which to structure the process of research and knowledge acquisition. Determining an appropriate theoretical basis for conducting research requires an examination of the elements of the theory looking for cohesion between the elements of the theory and the objectives of the study. After exploration of different theories, and consideration of the aims of the research, life course perspective theory presented as the most appropriate and logical theory as a foundation for the project. The life course perspective theory, with components of trajectory and transition, affords a clear association with the aim of exploring mid-life adults experiences of caring for an older person and consequential perceptions and planning for the own future ageing. Previous studies have been selective in the use of a single component of the theory to explore aspects of ageing.
However, the researcher considered the interdependent elements of trajectory and transitions are intrinsic to this study. From a pragmatic position, acknowledging the valuable characteristics of both qualitative and quantitative paradigms, the logical methodology to adopt for this study was mixed methods. Drawing on varied processes the methodology incorporated objective and subjective elements to explore participants’ experiences, reflections and expectations. The mixed methods research methodology and methods utilised are described in the following chapter.
Introduction

The following chapter describes the methodology shaping the study and details the methods utilised for both the qualitative and quantitative phases of the study. The mixed methods research design is discussed providing clarity on the specific approach taken. The methods are explained including ethical considerations designed to protect participants, sample recruitment, data collection and analysis, and the means of ensuring trustworthiness or validity for each phase of the research. The first phase of the study involved the utilisation focus groups and interviews to explore participants’ experiences of caring for an older person and the associated issues, along with reflections on how these experiences have influenced ideas of their own ageing and age-related needs. Data from the first phase was used to inform a survey questionnaire; the second phase of the study.

4.1 Methodology

The theory that provides a basis for research can also be termed a paradigm as it is the paradigm that sets out the objectives and expectations of the study and influences the manner in which knowledge is uncovered and meaning formed (MacKenzie & Knipe, 2006). Traditionally, research processes have been linked to an epistemological position or philosophical suppositions about knowledge, to the character of reality or ontology, and the manner in which knowledge is gained or methodology determined (Patton, 2002). One such paradigm is that of pragmatism which has been seen as contributing to the development of social science research (Tashakkori & Teddlie, 2003). Pragmatism respects both objective and subjective positions but also recognises that “both knowledge and social reality are based on beliefs and habits socially constructed” (Pansiri, 2005, p.197). Therefore going beyond the constraints of remaining within either the qualitative or quantitative paradigms, a pluralistic approach seeks to attend to the research problem in deriving knowledge.
(Creswell, 2003). While it is recognised that purists believe the qualitative and quantitative paradigms, coming from very different world views, are incompatible, it has been argued that pragmatists value a process that integrates both perspectives within a single study (Onwuegbuzie & Leech, 2005). A pragmatist accepts that the development of ideas arise within groups and in response to a particular context or changing circumstances (Pansiri, 2005). Like Tashakkori and Teddlie (2003), MacKenzie and Knipe (2006) consider the philosophy of pragmatism lends itself to research designs involving mixed or multiple methods. Approaching the study from the position of a pragmatist and with an interest in the individual’s experiences and reflections it was natural to focus on a methodology within this paradigm.

The research methodology ensures there is cohesion between the overarching questions or hypotheses and the design employed to answer these enquiries. The current trends in sociological research follow three distinct pathways: the quantitative stance drawing on empirical evidence; the qualitative position primarily concerned with narratives; and the mixed methodological perspective which draws on paradigms such as pragmatism (Tashakkori & Teddlie, 2003). The “worldview of pragmatism” has lead the development of mixed methods research designs that recognise the significance of historical and social factors and multiple methods of data collection (Evans, et al., 2011, p. 277). The mixed methods research design acknowledges the strengths and diversity of both the qualitative and quantitative paradigms to explore subjective and objective knowledge. Research employing mixed methods is recognised as increasing the confidence of accurately capturing the essence of the phenomena under study leading to a more holistic perspective (Adami & Kiger, 2005). The following section examines mixed methods research with reference to both qualitative and quantitative paradigms and explores the process of triangulation.

4.1.1 Mixed Methods Research

Mixed methods research has been increasingly finding favour among health professionals and social scientist as a means of ascertaining the views of the participant group as well as seeking answers from the wider population (Evans, et al., 2011; Greene, 2008). Gaining greater understanding of the issues being studied validates the importance of integrating research methods that traditionally reside in either the qualitative or quantitative paradigms (Adami & Kiger, 2005; Greene, 2008). Although the purist views these paradigms as incompatible, the pragmatist advocates the integration of both approaches within a single
study, employing the strengths and wisdom of each design to gain a better understanding of social phenomena (Johnson, Onwuegbuzie, & Turner, 2007; Onwuegbuzie & Leech, 2005). Denscombe (2008) and Onwuegbuzie and Leech (2005) go further and claim mixed methods research is the third paradigm. Mackenzie and Knipe (2006) contend that mixed methods has no recognisable philosophical basis but do acknowledge that pragmatism is the underlying framework. The doctrine of pragmatism reflects the mixed methods researcher’s acceptance of both single and multiple realities and an orientation to solving practical problems. Knowledge obtained from the pragmatic position is pluralistic with an orientation to reality, interest in problem-solving, and consideration of consequences of actions (Cresswell, 2003). The pragmatic approach acknowledges the importance of social and historical contexts. Bergman (2010) argues that mixed methods research is ideal for the exploration of how meaning is constructed and gaining an understanding of how respondents “make sense of their experiences or report on attitudes in interviews or questionnaires” (p. 172). The methodology appears to be particularly well suited to the complexity inherent in social inquiry whereby the differences in the qualitative and quantitative frameworks are deliberately incorporated to enhance understanding of perspectives (Greene & Caracelli, 1997).

Within the framework of mixed methods research Brannen (2005) describes four outcomes of combining data collected from both qualitative and quantitative approaches. Labelled corroboration, elaboration, complementarity and contradiction, these terms identify differing purposes and techniques of analysing and linking data. Data collection may occur simultaneously or sequentially, depending on the rationale for the mixed methods study (Creswell, 2003; Johnson, et al., 2007). The focus of the study guides the researcher to determine both the outcome of combining data and the time sequencing of collecting different forms of data.

The mixed methods approach recognises the importance of the individual’s viewpoint as well as taking the opportunity to extend the exploration to a more empirical method of data collection such as a survey. A study design that aims to seek knowledge about individuals’ experiences and reflections and then complement this with a more extensive group of respondents is ideally suited to the mixed methods research approach. For this study a dual approach was employed; firstly from the qualitative perspective, followed by a quantitative position. Such a process is known as the sequential design (Cresswell, 2003). This is where either the exploratory process is followed by accessing a large sample from which generalisations can be drawn, or theories are first tested on the wider population then explored with a few individuals.
Methodology and Methods

**Triangulation**

Within the mixed methods research design the data collection and analysis process used a type of triangulation. There are varying forms of triangulation, all involving multiples of investigators, theories, sources of data collection, or methods (Adami & Kiger, 2005; Cowman, 2008). The varieties of triangulation with distinctly different characteristics are:

1] Data triangulation involving different data collection sources within the same study
2] Investigator triangulation which employs more than one person to collect and analyse the data
3] Theory triangulation where many theoretical viewpoints and hypotheses are used to draw conclusions from the data
4] Methodological triangulation which utilises one of two methods:
   a) a combination of approaches from within the same research paradigm such as qualitative, or
   b) a mixed method approach from both qualitative and quantitative positions with the aim of achieving convergent validity.

(Watson, McKenna, Cowman, & Keady, 2008, p. 270).

Each form of triangulation outlined here varies considerably therefore appropriate application to the research question requires consideration. The research question focuses on the perceptions and expectations of mid-life adults regarding their ageing and future support needs derived from reflections on the experience of caring for an older person. The method chosen as best suited to address these factors is methodological triangulation, but more specifically the mixed method approach. To add a further dimension the methodology chosen was a sequential mixed methods design with a two phase approach; firstly exploring the qualitative aspect, followed by a small quantitative survey. The findings of the two phases are brought together to evaluate congruence between participants’ experiences.

The mixed-methods process, sometimes referred to as ‘between-method’, is a recognised means of securing a more in-depth understanding of a phenomenon with multiple measures of a single concept increasing the possibility of convergence of findings (Adami & Kiger, 2005). While the process can be complex, as it involves two diverse theoretical perspectives, it does afford the opportunity to confirm the findings from one source of data with another source to achieve greater “completeness” (Foss & Ellefsen, 2002, p. 244). In relation to the research question mixed method triangulation allows for both exploration of the topic of interest with individuals as well as seeking more extensive data from a wider group of the
Methodology and Methods

target population. One of the criticisms of qualitative research is that the participant's experiences are accepted without critique. Equally, quantitative research has been disparaged for failing to acknowledge the impact of personal experiences of a phenomenon on the individual. The strength of triangulation is that it has the capability of producing rich, extensive data which can be validated by information from another perspective affording the prospect of achieving consensus (Watson, et al., 2008).

The greatest challenge of employing two very different methods of studying the same phenomenon arises from endeavouring to maintain equal emphasis on both epistemological positions (Foss & Ellefsen, 2002; Lambert & Loiselle, 2008). One way of addressing the problem of equity is to focus on the underpinning theory. From the life course perspective both qualitative and quantitative paradigms are recognised, with knowledge gained from both the richness of individuals' perspectives and the quantifiable data leading to a position described by Foss and Ellefsen (2002) as a "continuum of knowledge" (p. 244). Polit and Beck (2010) argue that a mixed method research design, comprising both qualitative and qualitative approaches, is complementary and represents two key forms of communication; numbers and words, affording the potential to enrich the body of knowledge of the area of interest. In recognising the complexity of health services and social phenomena, triangulation of methods aspires to greater knowledge than can be obtained from a single epistemological position. The research design of this study applies a form of triangulation to guide the data collection on participants' experiences and reflections associated with ageing care needs.

The sequential mixed methods research design was coherent with the exploratory nature of the study and the objective of uncovering the participants’ experiences and reflections on their own ageing. To further explain the study design it is necessary to elucidate differing paradigmatic approaches. As the research employed both a qualitative design in the form of focus groups and face-to-face interviews, and a quantitative descriptive survey, each of these means of collecting data will be discussed, with reference to the appropriateness of the tools, advantages and disadvantages, and contribution to the research process.
4.1.2 Qualitative Research

Qualitative research takes as its premise an undertaking to explore the views, perceptions and experiences of individuals related to the phenomenon of interest. Knowledge that emerges from such exploratory studies is valued for contributing to some understanding of the human experience (Polit, et al., 2001). Qualitative research has been criticised for its lack of objectivity and validity error (Paley, 2005). One of the characteristics of such research is a striving to understand the area of interest from a holistic perspective; as in this study which seeks to understand the experience of caring for an older person and the ideas and influences arising from this experience. Polit, et al. (2001) acknowledged human experiences and thoughts as complex and that “truth is a composite of realities” (p. 15). Recognition that individual experiences, and reflections on these experiences, vary between people is valued by researchers who aim to achieve greater understanding of a particular phenomenon. However, such acceptance of variable realities can be criticised by those who prefer the surety of empirical statistics. Paley (2005) is particularly critical of the concept of “multiple realities”, which he regards as the antithesis of credible research (p. 197). In a discussion that centres on the discord between subjective and objective approaches to research Paley defends the positivist paradigm. The argument Paley proffers, however, neglects to acknowledge the unique nature of an individual's life experience and how this event can shape that person's subsequent actions and attitudes. Exploring the personal experience and its effects on thoughts and ideas is of significance to understanding how a person makes decisions and plans for their future. Such information cannot be discounted because it is not quantifiable but must be acknowledged as part of the rich tapestry of life.

The main proposition of qualitative research is that it acknowledges the contextual nature of life experiences and places value on the descriptions afforded by the participants' self-reflection (Benner, 1985). The basis for the methodology is recognition that people interconnect with their world, each having an effect on the other, and as a consequence the person’s experiences and perceptions are unique to them (Sadala & Ferreira, 2002). It values the relationship between the researcher and the participant as a means of exploring the lived experience and where people, their environments, and social networks are seen intrinsically bound together (Weaver & Olson, 2006). Through the study of subjective experiences as as described by the participant, the researcher gains greater insights into human nature specific to the area of interest (Maggs-Rapport, 2000). It must be acknowledged that in interpretive studies there is always the risk of the researcher's own views influencing their interpretation of the data. Therefore, it is imperative that the
researcher sets aside any preconceived notions and becomes open to the participant's descriptions of the phenomenon. The researcher’s prior assumptions or bracketed biases can be integrated into discussion of the findings at a later time (de Witt & Ploeg, 2006; Sadala & Ferreira, 2002). Likewise, the researcher-participant relationship can also influence the nature of the data obtained, requiring sensitivity in how the interview process is managed to prevent contamination of the participant’s expressions by the researcher’s viewpoint.

Descriptions derived from qualitative studies provide a deeper understanding of the participants experiences, but with minimal explanation of how this self-reflection may lead to action or change in circumstances for that individual. Knowing the meaning of an experience from the person who has lived through a particular phenomenon is of value in itself. However, for the purposes of this study it is also important to draw out the person’s reflections and response to this experience; how the event has shaped their ideas and intentions for the future. Recollections provide understanding of the individual's experience of a particular phenomenon. Reflection on the experience, on the other hand, enables the person to critique the influences resulting from the experience.

Participants in the focus groups and interviews were asked to ‘tell their story’ about caring for an older person which was regarded as an important element in this exploratory study. The story-telling process was followed by a series of question prompts to guide the participants toward the goal of elaborating on the positive or difficult aspects of caring for an older person, contributions to caring by other family members and how the participant envisaged their life as they aged. These prompts aimed to seek participants’ reflections thereby gaining insights into the factors that influenced their plans and aspirations that would shape their future older years. Creswell (2003) identifies the use of both open- and closed-ended questions as valid tools for gathering data in mixed methods research.

Within family relationships there is the potential for intergenerational influences on perceived expectations, behaviours and attitudes that shape, establish and maintain family practices. These influences may be generated by historical traditions, religious affiliations, contemporary societal changes and future aspirations (Allen, et al., 2000; Piercy & Chapman, 2001; Strawbridge, et al., 2002). There can be multiple interpretations of the influences and experiences for each participant therefore the goal of the inquiry must be to garner an understanding of the participant’s perceptions and experiences of the phenomenon of interest (Polit, et al., 2001).
Methodology and Methods

An important element of a study is supporting the reflective process as a means of drawing out participants’ ideas, based on past experiences, about their life situation and plans for the future. Reflection enables the individual to shed light on how they may respond to environmental conditions and relationships or choose to consciously change their lives as a result of past events. The validity of articulated perceptions cannot easily be challenged due to the unique interplay between the past experience and subsequent reflection that constitutes that person’s reality (Maggs-Rapport, 2001). It is important to acknowledge the exclusivity of each person’s experiences and thoughts, even though resonance may be evident with other people undergoing similar life events.

Reflecting on an experience and the associated social, political, cultural, gender or economic context contributes to the way a person shapes an understanding of their world (Weaver & Olson, 2006). The historical influences and contextual factors are important in providing understanding and perspective to the person’s insights and reflections of an event in their life. These elements are closely aligned with the nature of this study where knowledge was initially gained through a process of dialogue and interviewing in a setting that fostered the participant’s recollections and ideas. The depth of participant descriptions and thoughts about the phenomenon can only enrich the quality of the study. The concept of researcher-participant communication; recounting experiences and explanation of social processes points to the appropriateness of focus groups and individual interviews as a tool of data collection.

**Focus Groups and Face-to-Face Interviews**

The key element of focus groups is the interactive aspect of the dialogue, where participants are encouraged to share anecdotes, ask questions and debate ideas (Duggleby, 2005; Kitzinger & Barbour, 1999; Wilkinson, 2004). In fact it is the collective aspect of this data collection method that “capitalizes on interaction within a group to elicit rich experiential data” (Asbury, 1995, p. 414). The advantage of focus groups in research is the ability to observe extensive interaction and discussion on a topic within a limited timeframe. They provide a forum for participants to share ideas and feelings and for the researcher to uncover factors that influence opinions and related behaviours (Berg, 2000).

The success of focus groups as a technique for gathering data is dependent on several factors. These include clearly articulating the purpose for the group meeting; group composition that encourages ease of interaction; a suitable meeting environment; and group moderation that facilitates sharing of experiences and interaction, and demonstrates
Methodology and Methods

participant respect (Côté-Arsenault & Morrison-Beedy, 2005). A well planned group meeting can be very dynamic and stimulate discussion amongst the participants generating wide ranging ideas on the identified issues. Berg (2000) offers focus group facilitators a set of basic guidelines to managing the group interaction while eliciting data and suggests that interaction between participants may even lead to solutions for individual problems. Hopkins (2007) noted that when the proposed discussion involved a sensitive topic a diplomatic approach was essential to facilitate the focus group process. He also considered small groups were more appropriate for interaction centred on personal experiences as participants would feel more comfortable recalling their thoughts and feelings in a more intimate setting. Managing sensitive topics by posing broad questions initially minimises participants feeling 'put on the spot' (Berg, 2000). Therefore, encouraging participant comfort is of primary importance to fostering the group interaction and discussions that form the research data.

The individual face-to-face interviews explored participants’ knowledge of their parents and grandparents ageing and how these older people were supported and experiences of providing support for older relatives. A family tree was utilised to depict the generations both preceding and following the participant. The chronological representation included notes on informal assistance provided to the older person from family, privately funded carers or formal support services from government agencies. Within the context of family support, participants’ perceptions of sibling and intergenerational involvement in older relatives care provided further depth to understanding the complexity of the issues at the centre of the study. The interview data was combined with the focus group transcripts for analysis but are also written up separately as family stories to illustrate the complexity of caring and how this affected family members. The inclusion of family stories can focus on the individual and their context as a means of providing a rich, descriptive picture of how the interviewee experienced the specific phenomenon (Hewitt-Taylor, 2002). The stories allow readers, with limited understanding of the topic of interest, to gain greater insight into the real life experiences and perspectives of the person entwined in the event (Luck, Jackson, & Usher, 2006).
4.1.3 Quantitative Research

Research within the quantitative paradigm is an approach favoured by pure scientists in particular as a means of testing hypotheses or theories (Watson, et al., 2008). Generally recognised is being located in the positivist ontological world view, many studies aim to find a definitive answer to a posed question. Research designs commonly used include experimental, quasi-experimental, between or within-subjects, cross-sectional or longitudinal, retrospective or prospective processes. Key features of quantitative research include the ability to apply interventions, manipulate variables, and make comparisons between subjects and groups (Polit, et al., 2001). For many studies conducted within the health science domain, such research designs are very appropriate as they provide the opportunity to examine cause and effect, allowing conclusions to be drawn with implications for healthcare interventions, health promotion and education. Examples of such research might be the link between low birth weight and developmental delay, or cigarette smoking as a cause of lung cancer (Polit & Beck, 2010).

Surveys

However, there are other research designs that sit within the quantitative paradigm that do not necessarily consider causal links but rather aim to seek extensive data regarding a specific phenomenon, and also may attempt, through analysis of the data obtained, to validate the perspectives of qualitative research participants (Parahoo, 1997). Three key forms of quantitative research have been identified: causal, descriptive and correlational (Polit & Beck, 2010). Survey designs are largely non-experimental and seek information regarding prevalence, distribution and also relationships between specific phenomena for the respondents. Such designs can be positioned within either qualitative or quantitative paradigms as they may involve different methods of collecting data such as by telephone, face-to-face interviews, or self-administered questionnaires (Polit, et al., 2001). In general, surveys aim to gather data from a larger and potentially more representative sample of the population, or in the case of a census the entire population of a country (Parahoo, 1997).

Formulating questions based on the data obtained in qualitative methods is a well-recognised process in sequential mixed methods research (Watson, et al., 2008). Such techniques may involve developing a questionnaire based on the issues defined by focus groups or individuals with the aim of ascertaining if these issues resonated with a larger group of people who fit the same sample criteria. Alternatively, data from surveys may be
used to develop a series of prompts to guide focus groups from which to gather more detailed experiential information.

One of the strengths of survey design is the opportunity to reach a large target population with reasonable ease. Self-administered questionnaires tend to be less expensive in comparison to telephone or face-to-face interviews where obtaining data from a large number of respondents is costly in both time and interviewer fees. Using a postal or web-based format also potentially enables a wider geographical spread of respondents. Additionally, the nature of a self-administered questionnaire has the potential of allowing the individual to respond more freely, confident of maintaining their anonymity.

However, there are disadvantages of this type of research such as the inability to clarify questions, not knowing whether the responded is actually from the target population or has completed the questionnaire independently, and the tendency for a low response rate. Use of the internet processes to administer a survey questionnaire has become more popular recently but also limits inclusion to only those people with access to computer and internet technology (Watson, et al., 2008). Although it is recognised that postal and internet surveys tend to have a lower response rate, the former method was chosen to reach as wide a target population as possible within a reasonable time frame.

The use of sequential mixed methods research was coherent with the exploratory nature of the study and the objective of uncovering the participants’ experiences and reflections on their own ageing.

4.2 Methods

The data for this mixed methods design study was collected sequentially in a process of exploration and discovery (Cresswell, 2003). The first phase of data collection involved six focus groups in various settings within the Auckland city urban region and five face-to-face interviews. Subsequently, a survey questionnaire was administered by post. Each aspect of these processes are outlined including ethical considerations, sampling and sample recruitment, data collection and analysis, and issues of reliability and validity.
4.2.1 Phase One Focus Groups and Interviews

Focus groups and individual face-to-face interviews were employed to gather data on the participants’ perceptions regarding future expectations of their own old age and care or support needs and how these might have been influenced by their current and past family relationships and experiences or observations of caring for older people. The discussion of family involvement in caring for older people also allowed the researcher to raise questions about participants' perceptions of the implications for their own children of their own age-related care. The data from interviews and focus groups were analysed and the interviews were also written up as individual family stories. The stories enable the reader to gain insights into the experiences of the interviewees and their families and how these experiences shaped the individual’s ideas on how their future ageing needs might be met.

Ethical Considerations

Approval for the first phase of the study was granted by The University of Auckland Human Ethics Committee on June 11, 2008 (see Appendix 1). Careful consideration was given to ensuring all ethical concerns were met. Important points such as risks and benefits, participant confidentiality and data storage, and the right to withdraw from the project without fear of consequences were clarified on the focus group and individual interview participant information sheets (see Appendix 2 & 3).

Sample Recruitment

Phase one employed both focus groups and individual face-to-face interviews. Potential participants were recruited through a combination of advertisements in the Auckland newspaper and posters placed on community centre notice boards. At the time of recruitment, the Auckland newspaper was delivered free to all households in the greater Auckland urban area (see Appendix 4 & 5). Due to a very limited response from the South Auckland region an additional recruitment process was used and succeeded in attracting more participants. The process of additional recruitment involved the researcher making direct contact with the communications manager of the Manakau City Council and a message was sent to staff using the organisations global email facility which provided information about the study and contact details of the researcher (see Appendix 6). This organisation was chosen as they are one of the larger employers in the South Auckland region with the potential to reach a very wide audience. However, inherent within the email system is the possibility of forwarding messages on to other people the initial recipient might consider was interested in the project. This process, often referred to as "snowball or
network sampling (Polit, et al., 2001, p. 236), attracted a further three people who contacted the researcher and subsequently participated in a focus group. The focus groups and face-to-face interviews were restricted to those living in the Auckland region. The reason for this was that the 2006 Census indicated that Auckland was inhabited by one third of the total population of the country, is ethnically diverse, with significant numbers within the 40-64 years age group (Statistics New Zealand, 2008), thereby providing a large potential participant group.

Criteria for participation included people currently residing in the Auckland region, aged between 45 and 64 years, and having the experience of providing some form of support to parents or older people within their family or social network. Provision of care to older people could be either within the community or during and following admission to a residential care facility. No attempt was made to seek or eliminate participants from any specific ethnic group however, as English was the language used to conduct the focus groups and interviews, the result was a homogenous participant group of mainly women, none of whom identified as Māori (the indigenous population of New Zealand). As a consequence of having no Māori participants, and considering it was important to seek the views and experiences of this population group, consultation was sought with the Tumuaki (Māori leader) of the University of Auckland Faculty of Medical and Health Sciences, regarding appropriate access to Māori people for the purpose of ensuring their voice was heard. The Tumuaki supported the organisation of a Māori focus group and identified a suitable person to invite participants and facilitate the meeting. She also provided a letter of support to the application for ethics approval from the University of Auckland Human Participants Ethics Committee (see Appendices 7, 8 & 9). The age inclusion criterion for the Māori Focus Group was amended on the recommendation of the Tumuaki to include those in the 40-44 age bracket. The rationale for widening the age range was in recognition of the lower life expectancy of Māori people and the possibility that provision of care begins at an earlier age for the adult children of older relatives.

In addition to the Māori specific focus group there were five focus group meetings held at venues across the wider Auckland urban area. Thirty six people self-selected to participate in the six focus groups and 28 of these indicated on the Consent Form that they would be prepared to meet for a face-to-face interview (see Appendix 10). Five focus group participants were invited to participate in face-to-face interviews. They were selected due to the diversity of their personal experiences of caring for an older person and involvement of the extended family in this experience. Each interviewee signed a consent form (see
Methodology and Methods

Appendix 11). The aim of the interviews was to seek more in-depth information on participants’ experiences of caring for older relatives and the intergenerational influences on caring from their parents and grandparents. The interviewees’ were asked to reflect on their plans and anticipation of their future ageing and support they might expect from younger relatives.

**Data Collection: Focus Groups**

The aim of the focus groups was to seek participants’ perceptions and experiences of caring for older people, filial responsibility, parental, societal, religious and cultural influences on care expectations, and thoughts on their own, potential or anticipated, ageing care needs, including their expectations of offspring for future support. A set of open ended questions was developed to guide the focus group discussions and individual interviews (see Appendices 12 & 13). These questions arose from clinical experience with older people and their families and also based on relevant literature.

The participants were expected to be strangers, brought together to reveal personal experiences and the researcher acknowledged that verbalising their thoughts and perceptions might cause a variety of emotions for each person. Being mindful of the participants’ feelings yet wanting to extend the discussion into potentially delicate areas required skilful facilitation. Although they had willingly offered to participate and had received written and verbal clarification of the study, the actual group meeting had the potential to recreate the emotions associated with supporting or caring for older relatives. Therefore it was important to establish a setting that encouraged people to express a range of emotions without feeling judged by the other group members. Each group meeting was conducted in a small private location with easy access to transport. Meeting rooms chosen were relatively small to encourage a more intimate and private atmosphere. The groups ranged in size from five to eight participants. Participants were welcomed and introduced to others as they arrived. Allowing a period of 15-20 minutes for social interaction over light refreshments before commencing the group discussion fostered a more relaxed mood which led more easily into the actual focus group discussion.

After reiterating the purpose of the focus group and requesting confidentiality, the participants were invited, in turn, to tell their story of caring for an older relative or friend. The term ‘story’ appeared to encourage each speaker to provide a sequential account of their experiences, and the rest of the group to listen attentively. The stories varied in length and depth of detail and many of the participants were visibly emotional during the telling of their
Methodology and Methods

experiences. Each focus group commenced in the same way and in each the participants were universally respectful of the story teller, not interrupting even when the story seemed very long or harrowing. As group facilitator, the researcher acknowledged each participant when they had finished relating their experience, and often commented on the other participants’ head-nodding, smiles and non-verbal expressions of recognition or sympathy. The story-telling process proved effective in drawing out the more reserved participants while gently keeping in check those eager to express their views.

The uninterrupted period for group members to relate their experiences set the scene for the lively, interactive discussion that followed. Although there were clear differences in experiences and attitudes, the participants appeared to accept the views of others and there were several instances of imparted knowledge regarding accessing specific services for the older person. Many of the participants were quite forthright in expressing opinions about services they considered less than optimal, or health professionals and family members who failed to meet their expectations. There was also considerable humour as people shared accounts of how they managed some trying situations, and this light-hearted attitude appeared to allow people to outwardly manage their emotions when the discussion covered disturbing topics. Having assured the participants that they were not obliged to answer any question meant that some choose to remain less vocal when challenging issues arose.

Data Collection: Face-to-face interviews

The aim of the face-to-face interviews was to explore the interviewee’s experience of caring for an older person in greater depth. The interviews also incorporate the added dimension of a pictorial family tree which depicted four generations from grandparents, to parents, the interviewee’s generation, and children, nieces and nephews. The family tree was utilised to illustrate the intergenerational aspects of supporting older relatives and potential influences on the individual’s views of their own ageing. Question prompts were also applied to provide a structure for exploring the interviewee’s experience and reflections (see Appendix 13).

Both the focus group meetings and interviews were recorded and transcribed verbatim to enable thorough analysis of the data. The transcribing was completed for all recordings by an administrator who signed a confidentiality agreement (see Appendix 14). The focus group and interview transcriptions were offered to the participants for review and alteration as they deemed appropriate with additional comments and amendments inserted into the data as requested. Data from the focus groups and face-to-face interviews was collected during the period of September to November, 2008. The Māori focus group was held in April, 2010.
Methodology and Methods

Data Analysis

In accordance with the qualitative methodology, a general inductive approach was applied to the focus group and individual interview data as a means of identifying common threads or patterns evident through repeated examination of the transcripts. Unlike deductive methods, which make predictions based on general principles or theories, inductive reasoning is a procedure utilised for exploring a specific phenomenon of which there is limited knowledge (Polit, et al., 2001). The inductive approach was chosen as a means of discovery due to the paucity of evidence with regard to influences on the expectations of future age related care needs for people with experience of caring for an older person. The NVivo8 computer software programme proved a useful tool in managing the extensive data (Rich & Patashnick, 2002). The transcribed data from each focus group and interview was entered separately into the programme. A repetitive process of reading the transcribed data alongside listening to the audio recordings enabled the researcher to group together similar phrases and comments into sub-categories for each focus group and interview in turn. Further analysis linked these sub-categories into the formation of major themes. These major themes along with the contributing sub-categories describe the participants’ experiences, perceptions and reflections of the phenomena of interest.

Maintaining rigor in the analysis process was achieved primarily through the iteration and contextualising of sentences, phrases, words and described behaviours or responses within the transcribed data. The secondary means of ensuring researcher validity entailed a review of the data, analysis process, and identified threads, patterns and emerging themes by another experienced qualitative researcher. In addition a researcher of Māori ethnicity reviewed the analysis of the Māori focus group themes that emerged from the transcribed data. The final means of establishing reliability of analysis was to use excerpts from the focus groups and interviews to illustrate themes or sub-categories; allowing the reader of the report to evaluate the veracity of the theme formation against the raw data.

Reliability and trustworthiness

Guba (as cited in Lincoln, & Guba, 1985) constructed a framework which is now generally accepted as addressing the reliability and trustworthiness of the research process for projects that reside within the qualitative paradigm. The fours components to Guba’s construct are credibility, dependability, confirmability and transferability. Maintaining fidelity in a qualitative study is derived largely through attention to collection and analysis of the data within these four spheres. Each sphere is addressed in relation to the literature and the research project. Shenton (2004) also confirmed Guba’s framework and reiterated the
importance of credibility in establishing trustworthiness in any qualitative study. Shenton’s views are echoed by Graneheim and Lundman (2004) who argue that credibility is met when the project report demonstrates confidence in the management and analysis of data and how well the categories and themes relate to information gained from participants. Another characteristic regarded by these authors as intrinsic to demonstrating credibility includes validation of data by participants. Shenton recommended employing different methods of data collection such as observation, focus groups and interviews as a means of strengthening the advantages of each tool while compensating for their shortcomings. He also suggested that the researcher developed a rapport with participants to encourage honesty, whereby they can more openly express their views.

For this project, the researcher implemented several of the recommended processes to maximise credibility in the qualitative phase. Firstly, both focus groups and individual interviews were used to gather extensive data on the topic of interest. Following each focus group the recorded data was transcribed and offered to the participants for validation; a recognised process of ensuring the data is faithful to the individual’s expressions.

Dependability refers to clarity in the description of the project design, methods of data collection, and analysis of data that would enable replication of the study by another researcher (Shenton, 2004). Graneheim and Lundman (2004) note that the interview process has the potential to develop or evolve over time and regard dependability as being the degree to which the data remains consistent over the period of collection. The study design and details have been clearly described in this chapter and the processes used are well recognised within the qualitative research field. To ensure consistency of discussion across the six focus groups and five interviews a list of prompts were devised and used to structure each session (see Appendix 13). Applying the same ordered questions to each situation enhanced the ability to maintain focus on the specific phenomenon of interest. Participants were also given equal opportunity to contribute to the data gathered. Such equity was achieved in the focus groups by firstly encouraging each person to tell their ‘story’ of caring for or supporting the older person then use of careful facilitation to allow individuals to offer their views without any one person dominating the group.

The process of confirmability provides clarity between the transcribed data and development of categories and emerging themes (Shenton, 2004). An important aspect of the process is reducing researcher bias thus allowing the participants views to be apparent. To ensure
such clarity is evident to readers of the study report an audit trail and the progression of decision making during analysis is required.

Finally, the transferability of the findings is achieved by providing a comprehensive description of the study with sufficient detail to enable the reader to garner a broad understanding of the findings (Graneheim & Lundman, 2004; Shenton, 2004). Not only must there be a good explanation of the culture, context, participants’ characteristics and data collection and analysis processes but excerpts from the data are requisite for the reader's recognition and understanding of the issues as described in the report. The four spheres of reliability and trustworthiness, first defined by Guba (as cited in Lincoln & Guba, 1985), have each been addressed to ensure the research meets the essential requirements of a well-executed study.

4.2.2 Phase two: Descriptive Survey

A survey questionnaire (see Appendix 15) was utilised with the aim of gathering data from a wider group of the population within the Auckland region. Key aspects of the experience of caring for an older person and reflections on future ageing needs for the participants in the focus groups and interviews were used in the development of the questionnaire. The questionnaire comprised three distinct sections: demographic, respondents’ experience of supporting an older person, and their ideas for how their own future ageing needs might be met.

Advantages of the self-report questionnaire include wider geographic distribution, anonymity for the respondent, and absence of interviewer bias (Polit, et al., 2001). Commonly recognised disadvantages are the potential misinterpretation of questions, difficulty in reaching the target population group and low response rate for mail surveys.

Development of Questionnaire

The survey questionnaire was developed over a period of time with consideration for relevance of the information in relation to the objectives of the study. A review of the literature which reported on research employing similar survey tools revealed a limited range of tools relevant to this project. However, three eminent researchers in the field of older people’s health and well-being, Drs Emily Grundy, Alexis Walker, and Hoong Chih were willing to share examples of questionnaires they had employed in previous studies. The questionnaire created by Chih (2006) in research conducted in the UK involving Asian-Indian
and British participants was most closely aligned to the some of the objectives of the current study. With Dr Chih’s permission, aspects of the tool, along with factors that emerged from the exploratory focus groups and interviews, contributed to the development of the survey questionnaire.

Comprising 39 questions the survey was divided into three distinct sections. Section one was titled *You and your lifestyle* and contained 15 questions which sought demographic information about the participant such as gender, age, ethnicity, family composition, housing situation and the state of health and fitness of the respondent, and the state of health and independence of their parents (if alive). The literature identified daughters as being three times more likely to care for ageing parents compared to sons (Lee, 1999; Spillman & Pezzin, 2000) making that information of interest to the study. Details of other dependents of the mid-life adult were sought as these factors were raised by participants in the first phase of the study as presenting time constraints and tension in supporting older relatives. Likewise self-rating of respondents’ health and fitness provided information on how physically able they were in providing functional support to the older person.

The second section called *Supporting or caring for an older person* was required to be answered only by respondents who had actually provided support to older people. The 13 questions considered the nature and frequency of the care provided, family influences on supporting older people, contribution to the older person’s needs by other relatives, and the provision of formal support for the older person.

The final section of the questionnaire titled *Planning for your own ageing*, was made up of 11 questions seeking to learn about the respondents’ ideas and plans for their own older years including financial provisions, housing, views on family and government funded support and how they pictured their future older years. Respondents were asked to identify their preferences for living arrangements, responsibility for funding their ageing support needs, and whether they could rely on younger family members to assist them as they grew older. The questions used a combination of forced choice, and Likert scales with the option to provide more detail as desired. Respondents were also asked to describe how they envisaged their living situation and support needs, if any, at the age of 75 years old.
**Pilot Study**

Watson, et al. (2008) recommended a pilot study be employed to test the feasibility of the questionnaire. A pilot study was conducted with ten people known to the researcher and who fitted the participant criteria. In addition to completing the questionnaire, the target group were asked to make comments on the readability of the questions plus the general layout, clarity and time taken to complete. Watson, et al. advocated comparing the questionnaire responses to determine congruence between pilot group respondents with close comparison equating to greater reliability. These processes confirm the face validity of the tool as evaluating what was appropriate for the objectives of the project (Polit, et al, 2001). In addition to comparing answers to the questions, respondents’ comments were considered and changes made to improve overall clarity and readability of the questionnaire. The data collection tool was tested a second time with the same participant group to confirm its feasibility and subsequently implemented in the revised format.

**Ethical Considerations**

As with the phase one all ethical considerations were addressed in such a way as to protect the potential respondents’ rights as research participants. The respondents received an information sheet outlining the purpose of the study and what was involved, risks and benefits, confidentiality, data security, and the contact details of the researcher and supervisor (see Appendix 16). The age range criteria was extended in accord with the factors associated with the Māori focus group and the potential for people in the 40-44 year old age group to have experience of caring for older relatives or friends. A consent form was not required as, in accordance with anonymous surveys, completing and submitting the questionnaire was regarded as consent. Approval was granted by the MoH Northern X Regional Ethics Committee Chairman on 11 May, 2010 (see Appendix 17).

**Sampling size justification**

With a random sample of 300 participants, Table 4.1 depicts the width of the 95 percent confidence interval for various percentage estimates. The concept of confidence makes an inference about the likelihood of the same proportion of the wider population responding in the same way to a specific question (Watson, et al., 2008). A sample of 300 was considered to be appropriate for this social research survey, and as it was expected that a response rate of 50% was likely to be achieved a random sample of 600 was drawn and questionnaires sent to these people.
Table 4.1:
95% confidence interval widths for different percentages and 300 respondents

<table>
<thead>
<tr>
<th>Estimated Percentage</th>
<th>Width 95% Confidence Interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>10%</td>
<td>±3.4</td>
</tr>
<tr>
<td>15%</td>
<td>±4.0</td>
</tr>
<tr>
<td>30%</td>
<td>±5.2</td>
</tr>
<tr>
<td>50%</td>
<td>±5.7</td>
</tr>
</tbody>
</table>

Sample Recruitment

Initially it was proposed to use the electoral rolls for the region to draw the sample, however, as the roll was formed prior to the 2008 general election it was probable that people had changed locations and the roll would not be as up-to-date as the Telecom residential telephone directory released early in 2010. Therefore, potential respondents were chosen from the Telecom residential directory. To generate a total of 600 potential respondents, based on the average number of entries per page and the number of pages from A to Z, each 400th entry in the directory was chosen (plus or minus one) by a process of counting through the printed version of the directory. A process was also used to ensure a reasonably wide geographic spread across the region from Albany in the north to Karaka in the south by breaking down the wider region into smaller areas based on the 2008 electoral boundaries. As each name was selected it was entered, along with the address, on a list under the associated electorate which covered the suburb of the potential respondent. The researcher used discretion by opting for the name above or below the 400th entry to enable as wide a geographical distribution as possible. An example of this process is presented below in Table 4.2 with minimum detail of the individuals selected to maintain confidentiality. Using the process described, the number of potential respondents averaged 31-32 people for each of the 19 electorates in the Auckland region. The process ensured that the postal survey reached a wide range of people from variable ethnicities and socioeconomic status.
Table 4.2:
Selection of postal survey respondents

<table>
<thead>
<tr>
<th>No.</th>
<th>Name</th>
<th>Address</th>
<th>Electorate</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>SA</td>
<td>Address in Henderson</td>
<td>Te Atatu</td>
</tr>
<tr>
<td>2</td>
<td>JA</td>
<td>Address in Titirangi</td>
<td>New Lynn</td>
</tr>
<tr>
<td>3</td>
<td>DA</td>
<td>Address in Favona</td>
<td>Mangere</td>
</tr>
<tr>
<td>4</td>
<td>TA</td>
<td>Address in Otara</td>
<td>Manukau East</td>
</tr>
<tr>
<td>5</td>
<td>DA</td>
<td>Address in Papakura</td>
<td>Papakura</td>
</tr>
</tbody>
</table>

The postal survey was mailed to 600 people early in June, 2010, with the bulk of the responses (n=89, 15%) returned within one month of being dispatched. Nineteen envelopes were returned indicating the addressee had relocated and a further 9 responded saying they did not meet the age criteria.

Due to the low response rate further participants were sought from employees of four large organisations in the Auckland urban area. The Human Relations Managers of the North Shore City, Auckland City, Waitakere City, and Manakau City Councils, the councils that now combined to make up the Auckland super city, were approached by telephone with all but Auckland City managers agreeing to allow recruitment of their employees for the study. A brief information sheet was distributed to employees of the three participating organisation through their internal email communication system (see Appendix 18). Recipients were invited to contact the researcher to indicate their interest, providing an address to which the participant information sheet, survey questionnaire and free post envelope was to be sent. Additionally, following email contact from the editor of the ‘Kiwi Boomers’ website information was posted on the site to elicit further respondents. A total of 40 surveys were issued in response to interest from these locations with 38 returned, providing an overall response of 127 from a total potential sample of 640 (20%). A flow chart representing the timeline of the survey is depicted in Table 4.3.
Table 4.3:  
Flow chart of participant recruitment

<table>
<thead>
<tr>
<th>Timeline</th>
<th>Survey Questionnaire Participant Recruitment process</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>June 2010</strong></td>
<td>600 recipients chosen from Telecom’s Auckland residential directory and sent the survey questionnaire, information sheet and return envelope by post.</td>
<td>89</td>
</tr>
<tr>
<td><strong>July-August 2010</strong></td>
<td>Information sheet made available to employees of Manukau City, North Shore City, and Waitakere City councils via the email communication service. Potential respondents provided their details via email to the researcher and were sent the survey questionnaire, information sheet and return envelope by post.</td>
<td>35</td>
</tr>
<tr>
<td><strong>July-August 2010</strong></td>
<td>Information was made available to subscribers of the Kiwi Boomers website. Potential respondents provided their details via email to the researcher and were sent the survey questionnaire, information sheet and return envelope by post.</td>
<td>3</td>
</tr>
</tbody>
</table>

**Total response from the recruitment process**  
127

**Data Collection**

The postal survey questionnaire and information sheet (see Appendix 16) and a free post envelope were distributed to all identified potential participants. The completed questionnaires were allocated a participant number (1-127) in order of return to the researcher. A database was created using the SPSS (Version 20) programme and data from the questionnaires was entered as they were returned.

**Data Analysis**

The intention of the survey was to fully explore the relationship between firstly perceptions and expectations of mid-life adults as well as subsequent sub-group analysis examining specifically gender, ethnicity, age and relationship status. Achieving a sample size of 300 would support this level of analysis; unfortunately, given the low sample size, it was considered not possible to explore these results in any level of detail. However, results from the survey were presented using percentages and were utilised to support the qualitative findings presented in chapters five and six. Formatted management of the numerical data provides greater understanding of the information obtained through this process. The data obtained from the survey and entered into the SPSS computer programme was then used to generate tables depicting the participants' options to forced
choice questions and Likert scales (Green & Salkind, 2004). The additional participant comments were grouped together in relation to each question with excerpts from the data included in the findings.

**Reliability and Validity**

Reliability is determined by the consistently by which a defined tool, such as a survey questionnaire, measures the elements of a particular concept whereas validity is established by the accuracy of the measurement (LoBiondo-Wood & Haber, 2010). The reliability of the tool is reinforced by the consistency by which it is applied on repeat measures. Reliability can be achieved by first testing the questionnaire with a small group of respondents who meet the same inclusion criteria as planned for the survey. Piloting the tool allows the researcher to ensure its feasibility by evaluating and comparing the respondents' answers alongside their comments on clarity of questions and general ease of completing the questionnaire (Watson, et al., 2008). However, the reliability or consistency of respondents to answer all the questions and provide a true response cannot easily be controlled.

LoBiondo-Wood and Haber (2010) reported that respondents may want to please the investigator and provide answers that are “socially desirable” rather than a true reflection of their attitudes or experiences (p. 287). Reliability errors in an anonymous survey can occur due to the researcher having no control over whether the respondent met the inclusion criteria, provided answers that reflected their experiences or answered all the questions posed. Such potential errors may result in the data obtained lacking consistency across the total respondent group. The advantage of an anonymous survey is the lack of interviewer bias which may enable the respondent to provide more honest responses. In an exploratory or descriptive study the researcher is not examining cause and effect but rather seeking more information about a phenomenon of which little is known. Therefore, the data obtained, however incomplete, contributed to the limited body of knowledge of the subject of interest.

The extent to which the questionnaire addresses the study’s purpose and accurately measures the concepts ensures the validity of the survey tool (Watson, et al., 2008). The questionnaire was developed in response to the issues raised during the first phase of the study where participants in the focus groups and interviews identified specific issues related to their experiences of caring for an older person and their ideas about their own future ageing needs. Therefore the questions were clearly linked to both the purpose of the study and concerns that arose from the focus groups and interviews which focused on the phenomenon of interest. Content validity of the tool was strengthened in four ways. Firstly, an examination of other tools, the results of which were published in peer reviewed literature
to determine their relevance and potential use for the current study. From this evaluation elements of Chih's (2006) tool were incorporated into the questionnaire. Secondly, the tool used a combination of well recognised and structured questions including forced answer, multi-choice and multi-option questions and Likert scales. Thirdly, the tool was repeatedly applied and refined with a pilot group, and finally, in collaboration another researcher with considerable experience, further refinement resulted in the questionnaire which was utilised to collect data for the study.

Conclusion

Chapter three outlines both the methodology that forms the foundation for the research project and the methods implemented to explore the phenomenon of interest. As the project involved a method of triangulation employing both qualitative and quantitative research designs, these processes are discussed with regard to appropriateness, advantages and disadvantages. A choice was made to explore the topic first by drawing on the experiences and reflections of participants in focus groups and interviews to identify specific issues and formulate an understanding from the perspective of the people involved. The findings of the focus groups and interviews were used to inform the questionnaire which was tested and refined by a pilot group of people who met the inclusion criteria then subsequently made available to potential respondents. At all times the ethical implications of both forms of research were addressed to ensure potential participants and respondents were protected from unnecessary distress or intrusion. The results of each process of data collection are detailed in the following chapters beginning with the descriptive explanations from focus groups and interviews, followed by findings of the survey questionnaire, and finally the deeper, experiential interviews written as individual family stories.
Focus Group and Interview Findings

Chapter 5

Focus Group and Interview Findings

Your whole life changes in focus ... you do become a parent of a parent and a lot is focused on them a lot of the time ... a lot of emotional energy. And it just impacts hugely and you're still trying to maintain yourself. You know we're the meat in the sandwich generation.

CFG

Introduction

The following chapter describes participant characteristics, themes and sub-categories with excerpts from the raw data to illustrate specific points. The focus groups are named for the geographical position in the wider Auckland urban region where the meetings were held with the addition of the Māori-specific group. Therefore the excerpts are identified by focus group or individual interviewee, for example; East Focus Group – EFG, West Focus Group – WFG, North Focus Group – NFG, South Focus Group – SFG, Central Focus Group – CFG, and Māori Focus Group – MFG, and individual interviewees by chosen name or pseudonym; Jenny, Clare, Anne, Pam and Suzanne.

Criteria for participation in the focus groups and interviews required participants to be currently caring for or have had the experience of caring for an older person. It was therefore relevant to learn of their experiences to provide a context for the later discussion on how these people were planning (or not) for their own ageing years. The themes are grouped into two sections: (a) experiences of caring for an older person, and (b) planning for future ageing. In section one the first major theme, Experiences of supporting and caring for an older person, explains the participants’ experiences and thoughts associated with their role of caring for the older person. Included within this theme are the subthemes of: Attitudes to older people; Supporting the independently-living older person; Accessing formal support for the older person; Stresses for adult children in supporting the older person; Variations and issues in family support of the older person; Positive experiences in supporting the older person; Māori participants views on caring for older people; and The hospital admission experience. The multi-generational household and family relationships is the second theme in section one. Within the second theme are the following subthemes: Circumstances
Focus Group and Interview Findings

leading to multi-generational living arrangement; Relationships in the multi-generational household; and Children's involvement in caring for the older person. The second section focuses on participants' considerations for future ageing, with subthemes of Participant's plans and ideas for their future ageing; and Prospects of support from the younger generation.

5.1 Participant Characteristics

Focus Group participants comprised of 36 adults residing in the Auckland region and aged between 40 and 64 years old. The age range was reasonably wide spread with the greatest number in the 60-64 age bracket. The characteristics of all participant focus groups and individual interviewees are combined in Table 5.1.

Table 5.1
Age, Gender and Ethnicity of Focus Groups and Face-to-face Participants

<table>
<thead>
<tr>
<th>Focus Groups</th>
<th>Age: 40-44</th>
<th>45-49</th>
<th>50-54</th>
<th>55-59</th>
<th>60-64</th>
<th>Gender</th>
<th>Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Male</td>
<td>Māori NZ</td>
</tr>
<tr>
<td>North</td>
<td>1</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>5</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>West</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Central</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>East</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>South</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Māori</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>Totals</td>
<td>2</td>
<td>7</td>
<td>8</td>
<td>7</td>
<td>12</td>
<td>3</td>
<td>33</td>
</tr>
</tbody>
</table>

The participants were asked to select from a list of possible relationships with the person or people they provided support for, either currently or in the past. Several of the participants indicated they had supported more than one older person but the person identified most frequently was their mother (n=27) followed by their father (n=16). Parents-in-law were recipients of care from six participants and one person indicated involvement in the support of grandparents. A further four participants identified an aunt, uncle or family friend as the older person they had supported. Therefore the strongest indicator for providing support to an older person was familial ties. Table 5.2 details the analysis of transcribed data using the NVivo8 computer programme to develop the major themes.
# Focus Group and Interview Findings

## Table 5.2
*Analysis of Focus Groups and Interviews data using NVivo8*

<table>
<thead>
<tr>
<th>Theme Tree Node</th>
<th>Descriptor</th>
<th>Sub themes and Related groupings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Attitudes to older people</strong></td>
<td>Comments about NZ society’s attitudes and values related to older people</td>
<td><strong>Attitudes to older people:</strong></td>
</tr>
<tr>
<td><strong>Older people living alone</strong></td>
<td>Descriptions of older people living and coping (or not) alone in their own home</td>
<td><strong>Supporting the independently living older person:</strong></td>
</tr>
<tr>
<td><strong>Providing support</strong></td>
<td>Comments on the type and amount of support provided to older people living alone Participants comments on trying to support older people or parents who live a distance from them Positive experiences of caring for the older person</td>
<td><strong>Improving/information to gain better assistance to meet the older person’s needs</strong></td>
</tr>
<tr>
<td><strong>Accessing formal supports</strong></td>
<td>Comments on experiences of accessing formal supports and how helpful (or not) these are Improvement/information to gain better assistance to meet the older person’s needs Services for older people</td>
<td><strong>Accessing formal support for the older person:</strong></td>
</tr>
<tr>
<td><strong>Stress of caring</strong></td>
<td>Comments on the stress of caring and making decisions for older people Participants’ experiences and difficulties in caring for</td>
<td><strong>Stresses for adult children in supporting the older person:</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>The changing relationship between the older person and adult child</td>
</tr>
</tbody>
</table>
## Focus Group and Interview Findings

<table>
<thead>
<tr>
<th><strong>Females as carers</strong></th>
<th>Participants’ comments on stress related to working and caring roles</th>
<th>Conflicting commitments for mid-life adults</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Variations and issues in family support of the older person:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Lack of family support contributed to mid-life adults’ experience of stress</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Positive experiences in supporting the older person</td>
<td></td>
</tr>
<tr>
<td><strong>Sibling support</strong></td>
<td>Participants’ comments on female relatives, especially daughters as carers of older parents or grandparents</td>
<td></td>
</tr>
<tr>
<td></td>
<td>How participants arrange sibling support to give them respite from caring for older relatives</td>
<td></td>
</tr>
<tr>
<td><strong>Issues for Māori</strong></td>
<td>Links between present situation and loss of Maori community and support structures</td>
<td>Māori perspectives on caring for older people:</td>
</tr>
<tr>
<td></td>
<td>Māori perspectives on caring for older people:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The impact of colonisation on Māori</td>
<td></td>
</tr>
<tr>
<td></td>
<td>The sense of a fractured family structure</td>
<td></td>
</tr>
<tr>
<td><strong>Hospital admission for the older person</strong></td>
<td>Comments about the experience of the hospital setting in the care and support of the older person</td>
<td>The hospital admission experience:</td>
</tr>
<tr>
<td></td>
<td>The hospital admission experience:</td>
<td>Standards of hospital care received by the older person</td>
</tr>
<tr>
<td></td>
<td>Services for older people’s health</td>
<td>Managing the older person’s discharge from hospital</td>
</tr>
<tr>
<td></td>
<td>Learning about support services entitlements</td>
<td>Learning about support services entitlements</td>
</tr>
</tbody>
</table>

### Major Theme: The multi-generational household and family relationships

<table>
<thead>
<tr>
<th><strong>Multi-generation households</strong></th>
<th>Participants’ comments about having older parents live with them</th>
<th>Circumstances leading to multi-generational living arrangements:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Grandchildren offering support and being involved in older person’s care</td>
<td>Long-term multi-generational co-residence</td>
</tr>
<tr>
<td><strong>Grandchildren’s involvement</strong></td>
<td>Grandchildren helping to care for the older person</td>
<td>Relationships in the multi-generational household:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>The importance of the mid-life adults’ partner in support of the older person</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Special memories and relationships</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tension in family relationships</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Children’s involvement in caring for the older person:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sharing household responsibilities</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Grandchildren assisting their grandparents</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Protecting grandchildren from caring duties</td>
</tr>
</tbody>
</table>
Focus Group and Interview Findings

<table>
<thead>
<tr>
<th>Major Theme: Expectations and plans for future ageing years</th>
</tr>
</thead>
</table>
| Plans for own ageing | Comments on thoughts, plans and preparation for own future ageing  
Participations’ ideas of how they will cope with their older years, including finances, housing and health  
Comments on own children proving support and care as they have done for the older person | Participants considerations for future ageing:  
Anticipation of longevity  
The importance of physical health and well-being  
Maintaining mental health and cognitive functioning  
Housing preferences  
Co-habitating with friends or siblings  
Communal housing and retirement villages |
| Not wanting to be a burden | Participants’ comments about own parents not want to be a burden or not being a burden to their children/relatives | Prospects of support from the younger generation:  
Companionship from grandchildren  
Modelling the caregiver role  
Recognition of potential conflicting responsibilities for adult children  
Participants’ desire not to be a burden to their adult children  
Expectations of government-funded support services  
Hopeful expectation of future support from adult children |
5.2 Experiences of supporting and caring for an older person

Apart from two older people described as a ‘family friend’ all of the recipients of support were relatives of the participant. Each participant had the opportunity to provide a detailed description of their experiences in providing support and many of these accounts identified issues that resonated across the groups. The complementary categories that form the first theme encompass issues related to attitudes toward older people; participants’ experiences of hospital admissions for the older person; accessing formal supports; coping with independently living but dependent older people and providing informal supports to meet their needs; the stresses associated with caring for the older person; variations in family support provision; and positive experiences of the relationship between the participant and the older person.

The following section provides details on the complexities involved in caring for an older person for family members or friends. Participants discussed perceived attitudes toward older people, experiences with hospital admissions for the older person and access to formal supports. Concerns for the safety and well-being of independently living older people revealed some of the stresses and burdens experienced by the participants. Challenges for family members were also raised by participants but there were also positive elements to the experiences of caring for older people. The Māori focus group participants identified specific concerns related to changes that have occurred for their whānau (family) and the impact this had on how they cared for their older relatives. Excerpts from the data are provided to illustrate each of these elements.

5.2.1 Attitudes to older people

Concerns were expressed by some participants at what they perceived as a loss of respect for older people in today’s society and how this translated to the support the older person and their family received. Comments included seeing older people only as a commodity and not a valued member of the community.

_They fill a bed in the hospital, which is revenue, they fill rest homes in the community…it is based around money…they’re not seen as particularly valuable._

_They are at the end of their life; they’re at the end of what they can contribute._ CFG
Focus Group and Interview Findings

I think it’s this whole perception of how valuable these people are as a commodity. CFG

Negative attitudes by employers of the carer toward their need to support the older person were raised with participants expressing concern about the ability to provide care under such circumstances.

I think we are handled very poorly, [by employers] as well as our loved ones ... there’s quite a lot to learn but I think a lot of it involves around how we value people. CFG

I don’t think employers look quite the same on looking after an old person ... perhaps that needs to be recognised more. You go to the hospital [with the older person] ... it can take all day or longer. So there needs to be recognition from employers, unless they’re getting to that age too [of having older relatives needing support] where you need to take time off. EFG

A commitment to supporting the older person, including being present when they attended medical appointments or were admitted to hospital, meant time from the participant’s place of employment. The need to increase support from family for the older person and respond to sudden, unplanned for needs created problems and worries for the participants. Many of the older people continued to live in the community but became increasingly reliant on family for various forms of assistance in order to retain some level of independence.

5.2.2 Supporting the independently-living older person

Participants talked about some of the problems they identified with respect to older people living in the community, either alone or as a couple. Of particular concern was the evidence of gradual decline in physical health and, for some, their cognitive functioning. Coupled with changing health was the determination of the older person to maintain their independent living status which resulted in considerable concern for most focus group participants. One participant described her 85 year old mother still living in the family home despite her changing health condition.

It’s [house] absolutely huge and she has loved it and loved the garden, so she desperately doesn’t want to leave there. But she has increasing failing health over the last 10 years. CFG
Increasing need for support services

Adjusting to the increasing need to provide support services to enable the older person to function at home was also discussed by the participants and the pressures older people can place on their family to meet their everyday needs.

She won’t accept any help herself so it puts us in the situation of being organiser, the bossy person who takes her to see a specialist about something, or goes to get the new hearing aid and things like that as opposed to her taking the initiative to do these things. CFG

My mother is still independent, just ... she’s got dementia. She lives not far from me in her own home....she’s coping quite well and so I suppose I’m just trying to help her in that balancing period where she’s pretty good but there’s a lot of things she can’t do. For instance, yesterday she couldn’t get back into the house after going for a walk ... she forgets to turn the handle ... so those sorts of things happen. NFG

It feels like my cell phone is always on, and we’ve had one 5am [call]. They’ve now got the things around the neck – you know a call system –so I’ve had one callout from the ambulance people wanting to go in and Dad was out in the shed fiddling about at 5am and had managed to press against his buzzer thing. Suzanne

He [father] became very ill very quickly – overnight – and in the next six months he had three hospital admissions of quite lengthy periods, six weeks at a time. Mum managed to survive at home with our support. She didn’t drive, so we would take her to visit Dad and things like that. Anne

Safety Concerns for the older person

Participants were also very concerned about the safety of the older person living alone, particularly from physical injuries such as falling or leaving appliances turned on with the risk of fire. One participant talked of her father who remarried later in life and developed alcoholism, and the dangers associated with his excessive alcohol intake.

So when she [her father’s wife] died he lived in the house by himself and was a big danger to himself because he had falls and left the stove on. NFG
Others talked of the older person’s forgetfulness and the inability to manage their daily activities.

*When my father was by himself, he would often come home with meat or something and forget where he’d put it and you’d go in a week later and there it was sitting behind the lounge suite. You know – terrible smell, stuff in the fridge that was rotten…it was awful but he just couldn’t be there any longer.* NFG

*He’d leave taps running….start making the breakfast at dinnertime…he won’t have a clue who most of the people that wander in and out are, or names.* Suzanne

One participant spoke of the growing anxiety she and her sisters shared in regard to the mental wellbeing of their mother who was living alone in the community.

*In a funny way [we] prided on her being really alert. Although she’s really frail physically, she’s been really alert of mind. And just in the last few months we’ve really noticed confusion, and sort of signs that maybe her mental capacity is not quite what it was.* CFG

Fears associated with the older person driving a car and the risks of having an accident were also expressed by several participants. The following excerpt demonstrates the dangers involved where, in this situation, the mother did not drive but was cognitively intact and the father could drive but was cognitively impaired.

*He has been diagnosed with multi-infarct dementia. So after they finally sorted his physical health issues out he and Mum kept puddling along still doing stuff. Dad stopped driving for quite a while and then he did drive a little bit…but he couldn’t remember where to go. So Mum would actually direct him and he would do the driving.* Anne

Eventually the family persuaded their parents not to continue driving which caused considerable distress for all the family. Another area of anxiety for the participants was whether the older person was taking their prescribed medications and eating regularly. There were also issues of the older person’s proximity to family members to enable the maintenance of close contact and casual support.
Focus Group and Interview Findings

The ideal solution would be a granny flat so that he [father] can still have his independence…his own living space, but that I could feed him up a bit more and make sure he was taking his meds and stuff like that. SFG

He [father] was never bed bound…even when he had the odd heart attack, when he’d come home from hospital, he was still able to get up and move around. He did the odd bit of gardening, because he was a very keen gardener, but we’d mow the lawns. Pam

They [parents] started to need a bit more help with things like changing the bed linen, so one of us would go and do that, take them shopping, whatever they wanted. Anne

However, Anne reported that, since her mother’s death, her father continues to live independently despite having dementia. She now supplies him with most of his meals and arranges to have his medications prepared in dosage packs as he is unable to manage either of these basic tasks.

As a consequence of constraints on participants’ available time access to formal services for the older person was important to support their daily care needs and lessen the commitments for the younger adult. Whether the older person had developed chronic medical problems, or had become less able to cope at home, the issue of access to formal supports proved challenging.

5.2.3 Accessing formal support for the older person

Several participants identified the difficulty of accessing formal supports to assist with the overall care the older person required, whether the older person resided independently or in the home of the participant. Arranging suitable supports was an ordeal, especially when they did not know what supports were available or with whom to make contact. Even when they knew the supports that would be needed; there was a delay in making such arrangements leaving the older person potentially without adequate services to meet their basic functional needs.

If you don’t know what the services are and you don’t know what your entitlements are, then you’re in a very poor position to argue for support. MFG
Focus Group and Interview Findings

Accessing the appropriate services is incredibly difficult even if you are an educated person. CFG

We learnt a lot about incontinence problems and products and things quite quickly, though it was quite hard accessing information and help. We really didn’t know where to find out about these things. EFG

They were ready and set to discharge her – I said “Could we get someone to just come in because I have to go to work during the day?”. Oh no that was going to take some days to organise and it was things like that that were really frustrating. I felt that in the end we were just very reliant on our own resources. CFG

I have no idea how people cope who have no idea about the health system. I’m pretty savvy about the health system, having worked in it, and we had problems getting what we wanted and what we needed. We had to get quite aggressive in the nicest possible way to achieve the outcomes that my parents wanted. SFG

Regional variations in support services
Provision of services for older people varied between regional areas. One participant described difference in support services in different locations that her parents and sister had over the previous ten years prior to their deaths. They had all required support services prior to their deaths but there was “next to nothing” (MFG) available to them.

It’s the variation of what’s available and the appropriateness of it all, it’s just so diverse here in Auckland. MFG

[There are] different services in the wider Auckland [area] – from one end to the other, the difference is huge. Hospitals have no duty of care. He [father] wasn’t [considered] safe to get up and out of bed in hospital [but] he was safe whilst being looked after by us at home. MFG

One participant described the problems her family faced when her father shifted into her home at the terminal stage of his life. She received support services for her father supplied by both the local district health board and palliative care services. However, if he stayed with her sister, to give the participant some respite, the same services were not available as she resides in different district health board region of Auckland.
Attempts to secure privately fund formal support services proved as difficult to obtain as services funded by the district health board, with one participant even employing a relative when no-one else was available.

*Even if you're willing to look around and look for the best and pay for it, it's just not there.* CFG

*Actually money doesn't work at all. I've got a wealthy brother-in-law who has said any amount of money for his mother. But it doesn't matter* CFG

*He [uncle] couldn't get enough support in the house. He ended up employing my sister-in-law to help him a couple of days a week – just so he could get enough break [from caring for his wife], so he could get some work done around the house.* WFG

**Appropriate support services for older people with dementia**

Participants commented on the difference in support services available for older people with disabilities compared to those with conditions such as dementia. In their view there was an inability to understand the specific needs of those who might be physically well but lack the cognitive capacity to function independently.

*I don't think there's very good in-home support for people with beginning dementia. We got offered somebody [to] come in and help shower my mother three days a week. Well Mum's totally mobile, it was useless…what I wanted from day one was someone to come in in the evenings, say 4pm, help her put a meal together. That's what I wanted and I couldn't get it.* NFG

*The services that are on offer are all about physical disability but in actual fact she needed help just putting together a few things. That's where the problem lies and now 18 months down the track she's actually getting worse in terms of her dementia and they're withdrawing services.* NFG
Focus Group and Interview Findings

**Older person’s coping with support service careworkers**

There were particular concerns when the older person resided independently and the informal caregiver had less oversight as to how they were coping. Some participants spoke of the anxiety the older person expressed about having a stranger in their home.

> My mother was quite a private person...[she] didn’t really like these strange people coming into the house, always felt she had to be up and ready for them, dressed, making them cups of tea, all that sort of thing, so she really didn’t like it. CFG

> We did get a cleaner in. Social services provided a housekeeper to come in one hour a week. She [mother] didn’t want a stranger in the house at all. EFG

Another participant spoke of parents who lived independently with her mother caring for her father who had dementia. Her mother seemed unable to accept that the services were to support her and felt the need to support the carer.

> Mum’s always worrying [saying] “What do I get her to do tomorrow?” and I say “Mum she’s there to let you rest in the afternoon and she can look after Dad”. There’s always a sense of having to kind of help the helper. EFG

Receiving short notice of changes in support workers was also distressing, especially if a comfortable relationship had been established between the older people and the support worker.

> I got a call from the agency that the helper would be leaving and a new one would be coming just the next day - so too bad if there was a relationship or anything. EFG

**ACC and Palliative care support services**

Nevertheless, there were positive experiences for some participants in the formal supports they received while caring for the older person. One participant spoke confidently of the extensive support her parent’s received after her mother had an accident where her ongoing care at home was provided through the ACC scheme.

> We always felt that if she had a stroke rather than an accident she wouldn’t have got that care and support. Clare
Another participant, whose father was suffering from terminal cancer, described the support they received from palliative care services when he came to live with them.

_They were absolutely fantastic; coming, encouraging, and offering services to us…we were coping [but] they were the backstop for us and that was absolutely excellent. I couldn’t praise them enough._ CFG

A Māori participant acknowledged the support she and her father received from a Māori health support worker which enabled her to cope with bringing her father, who was suffering from dementia, to live with her in Auckland.

_I know my whakapapa [family lineage]. I know I’m Ngati Whatua [tribe]. So off we went to [to the Clinic]…within a week we had services put in place…and that was heaven for me._ MFG

Accessing formal support services to supplement the care provided to the older people by the participants presented challenges for many although specific providers such as ACC, palliative care services and a Māori community group proved to be positive in their response to the needs of the older person and their informal caregivers.

### 5.2.4 Stresses for adult children in supporting the older person

For many of the participants, the circumstances of providing assistance to the older person created emotional turmoil. They worried about the responsibility placed on them and the difficulty of making decisions for the person. Concerns were expressed about the changing relationship with the older person as their customary roles altered and the emotional consequences. Some participants also spoke of how taking on the role of carer impacted on the other responsibilities such as employment and child care. There were comments about putting aside life plans in order to support the older person and how they felt about these circumstances. The following excerpts highlight the profound sense of responsibility shared by participants as they discussed their experiences of making decisions on behalf of the older person.

_Sometimes our loved ones are so beyond it that they couldn’t care less what happens to them but the onus is on us and it’s huge, it’s a huge demand._ CFG
Focus Group and Interview Findings

It’s hard when you’re, you know, the chief person making decisions. SFG

When I made decisions for my Dad, the angst of thinking this is the end of his life. I am deciding ... do they increase his morphine to a semi-comatose state. Do we do this, do we do that. Thinking I’ve never had practice at doing this for someone so close to me in my own home. CFG

I think we take it very seriously – the responsibility of it - making decisions, making arrangements – you keep adding it to the pile of working, family, and everything else you’re already doing. CFG

The changing relationship between the older person and adult child
For some participants there was the realisation that the relationship they had previously shared with the older person had subtly altered with the increasing dependence of the older person on the younger person to provide support. One participant spoke of the emotional distress she and her sister experienced when their widowed father wanted to remain living with one or other of his daughters rather than move into residential care even though his physical needs were greater than they could cope with any longer.

Your whole life changes in focus … you do become a parent of a parent and a lot is focused on them a lot of the time … a lot of emotional energy. And it just impacts hugely and you’re still trying to maintain yourself. You know we’re the meat in the sandwich generation. CFG

We had that discussion. “Oh you don’t care about me, you don’t want me. Please can I stay”[father] … you know the big guilt trip which was very hard. EFG

Conflicting commitments for mid-life adults
Several participants commented on the conflicts they felt when trying to cope with the older person’s needs alongside responsibilities to their own family and employers. One participant talked about the challenges for her and her sister of frequently asking for time off from their places of employment to deal with their mother’s increasing needs. Finally, they both resigned from their positions and worked out a system of sharing their mother’s care. Others talked of the pressure of the older people’s expectations alongside the needs of their children.
Focus Group and Interview Findings

It was a lot of work and she [mother] expected us to run after her like Dad did. She expected us to come and visit her every day. We had to get her to realise that we couldn’t run after her every day. WFG

I’ve got little kids, mine are nine, and just turned 14 ... so I’m sort of stuck because I can never do enough for either generation. EFG

Currently I work, like everybody else, 60 plus hours in a week so the rest of my time is spent caring [for mother] basically. CFG

For some participants, the sense of responsibility in providing for the needs of the older person and being immediately available to them has meant they are less likely to pursue activities of personal interest. One participant described a rare holiday she and her husband took after several years of caring for her mother in their home. The deterioration in the older woman’s health resulting from their absence and her refusal to eat lead the participant to suggest such trips would no longer be possible while her mother was still alive.

We never kind of get away because we’re kind of stuck, so we had a caregiver in from an agency. They did their best but Mum just wouldn’t eat properly – you know how people kind of get set in their ways and we did our best to leave a list of what she’d eat and what she wouldn’t. She got quite sick and ended up in hospital. I think it does impact your ability in life outside the home because we really can’t leave her. NFG

The following excerpt epitomises the challenges and emotions many participants faced when taking on the responsibility of supporting the older person and how this impacts on other areas of their lives.

I personally have taken on a huge sense of responsibility and it doesn’t always come easily because you have your own plans and dreams – but you’ve got quite an overriding sense of responsibility. So you might have to put a bit of a lid on your own adventures, you know that may or may not take place. I guess that makes planning, not heavily, but fleetingly you might feel a bit resentful. CFG
One aspect of supporting the older person that created considerable concern for participants was living in a distant location and having difficulty getting information.

*We knew nothing about what was happening to her [mother]. I think we should have gone along to the GP and had a conversation about what to expect and what we could be doing and what she should be doing but we knew nothing. So she was definitely going downhill and we were a long way away and she just had a heart attack and died at home.* EFG

*She was independent for most of her life but sadly she went into hospital after having a fall. At that stage she was living down country and I was living in Auckland. It was very hard from a long distance, flying down and driving down most weekends to actually get information.* NFG

Comments from many participants indicated the responsibility for the older person was eased if shared with other people, particularly siblings in the case of parents. However, such mutual support was not always available for a variety of reasons. When the support of other family members was considered unequal the participant reported increased stress and resentment for the situation.

### 5.2.5 Variations and issues in family support of the older person

Participants spoke of the contributions of other family members made to assisting with the care needs of the older person. For some participants arrangements for providing support for the older person developed amicably with their siblings; each contributing as they were able.

*I’m not the only one involved in their support in that I have two brothers and two sisters. So there are five of us, so the load is nicely spread out, which is quite good.*

SFG

*We’ve started talking as a family, looking in the next probably six to twelve months, what the alternatives for Dad will be.* Anne

For some families the distribution of caring activities was based on the individual’s particular skills or relationships with the service providers. One Māori participant described how the
Focus Group and Interview Findings

carer for the older person was chosen by the whānau based on their perceived personal attributes and known ability to manage an older person's needs.

*My family knew I was able to talk to the doctors, so I was always asked to do so. Mediating role, duty of care was my role as I was the eldest. I was conscious of that at a very early age. Known my whole life I would end up doing this. Dad was still farming at 84 but became forgetful and ought to be cared for. Cousin said “Come home”, so I did. MFG*

Another Māori participant described how she took responsibility when the family would not recognise the older person’s need for assistance.

*The most difficult thing for me was actually my family unfortunately. It was my family, you know refusing to realise you know what was happening, and because I've always done it I could cope. MFG*

One participant described how she and her siblings worked together to share the support needs of their ageing parents, and now that their father was living alone in the community they were continuing to address various aspects of his needs.

*We didn't sit down and discuss it, it just kind of all evolved as the situation evolved over the last two years. When they [parents] were having a lot more hospital appointments I tended to do those because of my medical background. But A [brother] does the GP [appointments] because he knows the GP and there's a good relationship already. So yeah it's just kind of evolved according to our particular areas of ability really. Anne*

*Lack of family support contributed to mid-life adults’ experience of stress*

However, for some participants there was no sharing of care or support for the older person. They talked of the stress they felt when coping with the older person’s needs and making decisions when they received limited or no support from other family members, particularly their siblings. The feelings such a lack of support evoked indicated considerable resentment by some and resignation by others. Some of the excerpts below also highlight the expectation in some families for the females, usually the daughters, to care for their parents while the son’s contributions were less than adequate.
Focus Group and Interview Findings

It's been really very stressful…it's been a very stressful time and I'm the only sibling in New Zealand which is very difficult. I phone my brother in England and the other one in America – I asked them if they could please come out, you know, because it's so hard. SFG

It was quite hard. My brother was around, he’s always been around, but he wasn't wanting to help at all – so I found it quite hard taking it all on myself. NFG

I’m one of two and my brother debunked completely. MFG

My brothers, one lives up in the far north and the other on is down in the deep south. So in terms of what they are able to provide its limited and neither of my sisters-in-law can cope with having Mum there very long. CFG

There's a lot of unfairness with the load because people know that some people won’t say “No” because it is about who they are and so, you know other people get away with a lot scot free. There’s more responsibility that can be shared. MFG

Another participant described her experience of caring for a father with dementia, how hard the role was and how the wider whānau ‘disappeared’. She expressed her resignation regarding the situation when saying “who wanted to care for an eighty year old with dementia” (MFG). However, while many of the difficulties and stresses associated with providing support were raised in the focus group discussions and interviews, there were also a few positive comments, particularly about their relationship with the older person.

Positive experiences in supporting the older person

Several participants, particularly within the Māori focus group, spoke positively about their experiences and relationships with the older person. One Māori woman recalled how she valued the experience of caring for her father.

*My dad was actually Pakeha [European ethnicity]. My mother died young so I didn’t get to have that experience of her in her older years. But I really appreciated my dad in his older years and also his perception of me as a Māori; that he expected that I was going to look after him until he died in our home.* MFG
One participant talked about the relationship she developed with her father as she cared for him, while another one admired her mother’s positive approach to life.

The most wonderful part of caring for my dad was the intense love that strengthens when you live with a person for seven years, 24 hours a day, seven days a week. You know that there are things that you have to do that other people would never have to do because he’s become older and becoming frail. Falling in love with your father – that would be the greatest happiness for me, absolutely – and that’s not incestuous – we know it’s the purest word, beauty. MFG

I look to my mother – despite whatever happens, puts a smile on her face and walks out the door - just have a laugh each day despite what’s going on. MFG

5.2.6 Māori participants views on caring for older people

The same list of discussion prompts was applied to the Māori Focus group as to the other focus groups. While the participants responded to these questions, their conversation and discussion was wide ranging. Several participants revealed their anger at the changes in Māori society as a direct consequence of the colonisation process. The ideas expressed that contribute to the theme of Māori perspectives included sadness at the loss of the small supportive communities, the loss of their land, and the loss of a safe environment. They also spoke of the whānau support structure that enabled the older person to be cared for in the home setting, and the desire to return to a lifestyle that has been lost. The following descriptions and excerpts are from the focus group where all participants invited to the meeting identified as Māori.

Participants talked about the Western liberal society and the “selfish greedy youth”. One participant said that many Māori consider reclaiming their cultural identity as “romantic” but she believed that “there is much about being Māori that ought to be reclaimed…and a caring extended family has got to be a priority for me”. However, the sense that modern Western society had negatively influenced attitudes to older people was also revealed in the following comment.
No one wants to look after the old, and why should you? You were raised to, in the
pervading culture, the dominant view is that you are raised to be independent. Now if
you are raised to be independent, why on earth would you care for anybody at the
end? That’s a contradiction, it’s ridiculous.

**The impact of colonisation on Māori**

There was evident anger at the influence of another, dominant, culture on the society of their
forebears and the impact of losing their land.

For me it’s not about changes that you can make, but being very angry about what
has happened to Māoridom since contact. Because I understand that if our social
organisations such as the extended family, whānau, hapu [extended family], were still
intact, I wouldn’t have to go begging…for services. When I recollect my own
grandparents…dying, and my maternal grandmother, and three months before they
died, the family were gathered and taking care, there were no questions asked. They
came, and they were there for three months. They gave up their income, or their
partner continued to earn and there were no questions asked.

Give me my land back and let me be able to do this for my own family.

There’s the Head Hunters at one end, there’s the Black Power at one end. There’s
thieving relations, there’s no reo [respect]. There’s ignorance everywhere. Now no
one is safe in that village, that two, three generations ago human beings, Māori
people were very safe. Their land was intact, their whole family worked on that land,
they fed themselves, they clothed themselves, they lived happily with each other, and
in two generations that has gone. And that’s what I want back.

Participants related stories of older people who had lived safely within a village setting and
were cared for by the wider community.

I hear stories about grandfathers...in the North. Quite clearly they were demented -
that Western society would call demented. But there was no problem, and you hear
them talk about Grandpa T, he wandered around…from this home to that home – he
was safe. That village that Grandpa T roamed around in now is no longer safe for
children.
Focus Group and Interview Findings

The sense of a fractured family structure

The determination to care for the older people was tempered by both the claim for services and the sense that the family structure was collapsing.

I acknowledge the help from Ngati Whatua [tribe], but I get very tired of hearing Māori people talking about this service, that service, this provider, that provider. I come from a family where you provide for yourself, and to get service from anywhere else is not a good thing. So that’s the contradictions, you’re raised in this way, you have to, to stay sane, to engage in the wider society, because your family has fallen to bits. And that makes me very angry; it also makes me very wise.

One participant expressed concern about Māori people being regarded as troublesome, especially in relation to their health needs, and her perception that the influences of Western culture was responsible for Māori people’s behaviour and attitudes.

I think it’s rather dangerous for, if it gets to the policy makers that Māori whanau are problematic. Māori whanau are problematic because of 200 years of contact with another culture. And that needs to get across to the health sector, who are only interested in treating disease at a particular cost, and preferably not at a cost to the government, and at a profit for those who are medical people. I don’t want it to get to the government that Māori people are a problem, we are not a problem.

For the group of Māori women who contributed to the focus group discussion there were many differing perspectives. Nevertheless, there was acknowledgement of the views expressed that displayed the anger and sorrow at changes brought about by colonisation and its influence on the culture of the Māoridom. Regardless of the geographical setting, ethnicity or time constraints for supporting the older person, admission to hospital raised further issues and distress for many of the participants.
5.2.7 The hospital admission experience

Participants recalled their experiences of supporting the older person when health issues or an accident resulted in their admission to hospital and what they perceived to be variable standards of care or services for older patients in this healthcare setting.

Standard of hospital care received by the older person

Participants provided examples of when the older person was hospitalised. There were comments on the level of care provided, especially if the admission was into a general medical ward rather than an area that specialised in older people’s health, and difficulties accessing information.

The medical ward that he first went into on the weekend, it was absolutely appalling care. And I guess if I hadn’t been a nurse…I would have probably not known why they were keeping him and what they were doing. EFG

We brought her up to Auckland, but with various times going backwards and forwards to hospital, this was a different hospital board, the family was just not kept informed. You had to battle all the time to get any information. NFG

I’d go up to find out and they’d tell me ‘Oh yes I’ll go to the chart and find out about the tests for you’ [and] they hadn’t even done the test. I was just brushed off, just a nuisance…I thought his care was appalling. CFG

Another participant described the difficulty in ensuring her father received appropriate medical care and the need to call on her brother, who is a doctor, to intervene.

They were withholding oxygen from him and I was kicking up. [I asked] “Can you page Doctor H” and they went “Who?” And I went “His son, Doctor H works here. Page him now”. My brother came up and barked, and they all ran around, and plugged Dad into oxygen, and he lived for 5 more years because of that. MFG

Some participants noted that even receiving food was a problem for these unwell, older patients with seemingly little effort made to ensure they were able to eat the food provided.
When they were in the medical wards, or something that wasn’t an old people’s ward, nobody helped with the feeding. EFG

My confidence in the hospital started to drop a little because I’d go up and visit him at lunchtimes and see his food sitting on a tray. Now he couldn’t feed himself. I had to get used to taking that role over and feeding him because I couldn’t go back to work thinking that his food’s sitting on the tray and he’s going hungry. WFG

We took her [mother] to hospital only for me to have to spend my days there feeding her because there was no one to feed her during the day….there was one day there the food came and they just put it to one side and just left her. SFG

There were times when it was easier coping with the older person at home rather than feeling they were not receiving adequate care from the hospital staff. One participant described how the family was involved with the care of her father who had renal failure and was receiving dialysis. He had had several hospital admissions but they were more comfortable having him at home.

My mother phoned up from the hospital saying “They’re not doing anything and he’s coming home”. The doctor was saying “You can’t take him out now - look it’s at your risk”. [I was] looking at the bloods to see that he wouldn’t die on the way home, then packing the dialysis up… Four or five of us could do stuff and the kids learnt…the mokopuna [children] could put needles in and hook the machine up cause sometimes the old man would forget to turn it off”. MFG

**Services for older people’s health**

However, there was acknowledgement of the value of the Older People’s Health services in the hospital from one participant.

If you don’t get referred to the geriatricians, you have a great deal of difficulty. As soon as we started into the geriatric ward we were much better with M when he actually ended up there. CFG
Managing the older person’s discharge from hospital

Several participants reported that notice of the patient’s impending discharge from hospital could come with minimal warning. If discharge was to be to residential care, this would involve the participant being put in the position of having to make a rapid decision on the most suitable place for the older person.

The worst thing for us was when the doctors decided to discharge a patient somewhere else, it was a speedy discharge – just like that – “you know you need to get this person into a rest home, hospital level care, all paid for, I’m going to discharge [him] tomorrow”. It was just instantaneous. You were meant to be able to do this with very little help from social workers and very little input. I found that very hard. CFG

When somebody is going to be sent home it’s going to happen yesterday, and suddenly, as a caregiver, you’re racing around trying to find somewhere...you’re literally going into rest homes and looking at a room with a patient in there and being told this patient is probably going to die tomorrow [so] you can have the room. I was appalled at what we were given. CFG

Learning about support services entitlements

However, for some participants, having the older person admitted to hospital proved a positive experience in terms of learning about the support services they were entitled to and having access to the appropriate people to ensure these services were arranged. One participant described her mother’s admission to hospital, which enabled them to access the services of a nutritionist, pharmacist and social worker, all of whom provided invaluable assistance.

She had a mild heart attack and actually did get hospitalised…it gave us a chance to tap into the system, which we really didn’t know terribly much about...The social worker assessed Mum with the three daughters present and we all participated [and] we have been able to have two hours care every morning at home – they set her up for the day, make sure that she’s had breakfast, so that’s a huge relief for us. CFG

Providing support to the ageing relative or friend has shown to be a complex and multifaceted experience. While the experiences may have varied, all participants were members of a wider family with partners, children, grandchildren and siblings. The experience of caring...
for the older person was not theirs alone as other relatives were affected also through either sharing in provision of support or carrying additional responsibilities within the family. These family experiences and the ensuing effect on relationships are revealed below.

5.3 The multi-generational household and family relationships

Some of the participants told of their experiences of sharing their home with the older person, which meant two or three generations living together. For these participants, the joint living arrangements had developed in response to either the older person’s need for close support or began as a process whereby the older person assisted with grandchildren but stayed on when the children had grown up. Discussions in the focus groups and further explanation from interviewees highlighted the complexity of multi-generational households and the action of reciprocity in care-giving and receiving. The categories contributing to this theme include the circumstances leading to multi-generational living, relationships in the multi-generational household, demonstrating care-giving to younger family members and grandchildren’s involvement in caring for the older person.

5.3.1 Circumstances leading to multi-generational living arrangements

Participants who had experienced sharing their home with both older relatives and for some, younger family members also, talked of both the challenges and the positive aspects presented by these circumstances. For some the duration of cohabitation was of short duration when the older person was unwell, for others the period was as long as twenty years. Jenny described the situation in which her father came to live with her in the last weeks of his life when he was dying of cancer. Up until then he had been living independently but with increasing support, however, the knowledge that medical treatment was no longer an option and his condition was terminal lead Jenny and her family to make the decision for him to move in with them.

We got him out of hospital and packed him up from home and said just come for the weekend, because he was quite reluctant to leave home and come. He didn’t want to live with us. And he said, “Oh alright, just till I get better. I don’t feel quite well yet”. So I said “That’s a good idea. You have the weekend with us and then we’ll see how you feel about going home”. Well he never did go home and he said later “When I walked out of the door I knew I wasn’t going home”. So he came and lived with us for six weeks and passed away at home with us. Jenny
**Long-term multi-generational co-residence**

One focus group participant related how her mother moved into her home to assist with grandchildren when the participant was unwell but her mother has never left. While the participant spoke very little of the individual family relationships, she did convey acceptance of the situation by her children. She also identified the act of reciprocity, and how the pattern and focus of support changed over the ensuing years as her mother grew older and needed more assistance while the grandchildren matured and gained independence.

*My mother has actually lived as part of our household for the last 20 years. She originally came to live with us in her early 70’s...to help care for our 2 preschool daughters...and she stayed. At the initial stage she was, you know, a huge assistance and then I guess we’ve progressively gone through the ageing process with her. So now she is 93, she is still semi-independent within our family but it certainly is getting to the stage...we can’t leave her on her own now. She did come and she had a huge contribution to the family. So in many ways the care we are providing now is just in return for all that’s been given. With our children, Gran has just been part of their lives. She’s always been there and my middle daughter doesn’t remember a household when Gran wasn’t there. CFG*

Another participant described her household situation which evolved after she was widowed and went to live with her parents and unmarried sister. Now, since her father’s death, the three women live together in reasonable harmony. Her mother is getting frail but is still very independent. However she has acquiesced to the daughters’ insistence of having a cleaner manage some of the housework. A further participant spoke of the situation that arose for her family when her mother came to live in a ‘granny flat’ beside the home she shared with her husband. Her married daughter lived in an adjacent house and her children grew up accustomed to their great-grandmother’s presence. She commented that with four generations living in close proximity her mother “just absolutely flourished” (SFG).

Participants who were closely involved in the care of the older person, including sharing their home with them, discussed how they managed to have a break by arranging for other family members to contribute to the care or arranging respite in a residential facility.

*Sometimes I can send my mother, as she is now, to my sister in Melbourne and I get a six week break. CFG*
Focus Group and Interview Findings

I don’t think she wants to go into a home, she says she’d rather stay with me as long as she can. This is the first time going into respite care this Christmas – so we can have a break because my brother lives too far away. EFG

For many participants, cohabitating with the older person was not their preferred option or even considered a possibility due to the challenges of medical conditions such as dementia or coping with strained relationships. In fact the nature of the relationship between the participant, their family and the older person was crucial to the comfort of shared accommodation.

5.3.2 Relationships in the multi-generational household

Several participants said the relationship they had throughout their lives with the older person contributed to the ease of coping with the older person’s changing needs. Jenny talked of the character of the relationship she had with her father and the involvement of her husband and children in the decision to move her father into the family home for the last few weeks of his life. Her three teenage children agreed to their grandfather living with them even though it meant one child relinquishing her bedroom for her grandfather.

The nature of your relationship before something like that [illness] happens often determines your choice; what’s best for somebody, what you can do. I was really pleased that my family, who we consulted before – we talked to our kids before we brought Dad home, you know, this is going to impact us and we didn’t know whether it would be longer than six weeks. It could end up being six months, who knows? Jenny

When visiting relatives questioned the relationship between one participant and her mother and sister, who live together, she said:

How do you describe your relationship? My mother said “I guess we’re flatmates really” and we didn’t get into a discussion, because that’s probably how; I mean we’re mother and daughters, that’s really how it’s been. So there’s been quite a lot of negotiation around space, psychological space, and the nature of the relationship. SFG
The importance of the mid-life adults’ partner in support of the older person

For other participants, family acceptance, especially their partner, was very important in ensuring the household was at ease. One participant commented that it was her husband who encouraged her to take her mother into their home as she become less independent and needed more assistance.

*When she [mother] was 90 she permanently came down and lived with me then…I got remarried and…because my new husband knew nothing else, I always had Mum there with me, he accepted her.* EFG

Another participant spoke warmly of the relationship her husband had with her father which enabled them to share his care needs, including personal care, and still maintain his dignity.

*They were really, really friends. Got on really well…very easy-going, the pair of them. But B [son-in-law] did say that he got really, really close to Dad because he was with him all day, every day. And you know I was really careful about the whole dignity with Dad. But towards the end he just needed a bit more care and I said to B, I said “Can you please just go in and do that?” And you know B’s just a very capable, easy-going sort of guy and he would do things for Dad, you know? Anything really, really personal and wouldn’t bat an eyelid.* CFG

Special memories and interpersonal relationships

Several participants considered memories were very important parts of the family relationships and were glad their children could recall happy events with the older person.

*It’s not until, I think, they’ve died, there’s a period that you actually, the children start remembering grandma sitting on the seesaw with them, and how she used to be, rather than the frail person that she became.* CFG

Participant Pam acknowledged the uniqueness of the situation when her widowed mother moved into a granny flat adjacent to the home she shared with her husband and beside her daughter’s family. She had no regrets with the close living arrangements as everyone got along quite well and her grandchildren had the opportunity to develop a good relationship with their Great-Nana. The situation continued for eleven years until her mother’s
Focus Group and Interview Findings

deteriorating health lead to Pam taking her into her home and providing daily care for several weeks until her death.

My granddaughter felt my mother was her property and we were really concerned as Mum aged, and particularly towards the last couple of months [of her life], of how we were going to deal with O [granddaughter] because she was the one who had developed this really strong bond. But…they just take it in their stride. She’s got so many good memories…all the kids have. Pam

Tension in family relationships

However, household harmony was not apparent for all participants, particularly when the grandchildren were teenagers, the older person exhibited less tolerance to the preferences of other members of the family and their behaviour was testing to deal with, or there was a difficult relationship between the older person and the informal caregiver.

So she [mother] came and lived with us and…V [daughter] would have been 12 or 13, so it was right through her teenage years, and there was that piggy in the middle of generations. It was really quite difficult. They had separate areas but V didn’t want to bring her friends’ home with Nana sitting there. EFG

One participant described the change in behaviour of her mother that lead to her developing ‘helpless’ characteristics when she came to live in her home.

The minute she [mother] moved into my house she stopped doing anything for herself – even got me to clean her false teeth…she sat in the chair, she said “Turn off that radio, I don’t like that radio station, put on the one I like”. The house had to be organised around her and, my husband is a very easy going man, and he found this very trying. EFG

Yet another participant described the problems she faced with her father’s behaviour in her home. She had not realised how his developing dementia had changed his personal habits which she could not cope with.

His [father] habits weren’t as great as what they could have been and we just couldn’t handle it after a month. That was long enough for us so we got him assessed, and…he went into a rest home. NFG
Focus Group and Interview Findings

Having a difficult relationship with her mother was put to the test when one participant’s siblings decided that she was in the best position to support their mother by living with her. Their relationship did not improve, but the participant felt she had fulfilled her duty to her mother.

I don’t like my mother and she never liked me [but] I agreed to move in. So I moved into her house with the two children and they were 10 and 13…I’d take her to the hospital appointments when she couldn’t drive and the kids would help out. SFG

Nevertheless, the same participant described how her mother taught her daughter to play the piano and both children to bake, acknowledging the benefits derived from the shared household. However the reciprocal arrangement of the younger generation caring for the older person varied between participants with many protecting their children from direct involvement in providing for the grandparents’ needs.

5.3.3 Grandchildren’s involvement in caring for the older person

Many of the older people supported by family members had grandchildren living in the same house or nearby. The participants demonstrated various views on the participation of these grandchildren in the support and care of their grandparents.

Sharing household responsibilities

Participants revealed that in general they had tried to shield their children from the need to be involved in functional support for their older relatives, more specifically helping with personal cares such as showering, toileting, dressing and taking medications. While some participants did not want their children to care directly for the older person they talked of the need for them to take on more responsibility in the family home to allow the participant to devote more time to the older person. Such responsibilities included taking on more household chores or simply spending time with the older person.

Really we’ve got five adults [participant and her family] ... we should be in a kind of adult flatting situation but still a lot of the stuff is still left to me. Their perception is that because I work part-time, I’ve got more time but that time is being spent more on Dad. Anne
At this stage we’ve got two of our adult children back living at home at the moment. So they are really good with Gran. EFG

**Grandchildren assisting their grandparents**

One participant described how her nieces and nephews learnt how to assist their grandfather with the intricacies of using kidney dialysis equipment; a process that supported the older man and meant he was able to stay at home rather than experience repeated hospital admissions. Another participant spoke positively of the support her young nieces displayed regarding their grandmother:

*It’s your turn, Nanny watch ... which I think it’s great that they take that responsibility on.* MFG

There were further examples given that indicated the grandchildren had provided more practical assistance, as one interviewee reported in regard to her disabled mother when she stayed with the family.

*I suspect that both A [daughter] and B [son] may have helped Mum to the toilet once or twice over the years when there was no one else around and she needed to go, but it wasn’t a regular thing. They both occasionally had to help physically with Mum, but more socially rather than physically.* Clare

Another interviewee provided a similar recollection of her children’s involvement in the care needs of her father who spent his last weeks of life in their home.

*She [granddaughter] would do anything for him…fetch him meals, help him up…help him clean his teeth. All that sort of stuff which, you know, H’s is not really like that really…I suppose it brings out the best in people or the worst in people…but the kids would all do anything. Whatever was needed, I could ask them to do something.* Jenny
**Protecting grandchildren from caring duties**

One participant spoke of protecting her children from direct caring so they could enjoy their relationship with the older person.

*They haven’t been so influenced by the having to give care side of it, because they haven’t had to, which is really nice to protect them a bit from that … so they can just get on and be grandma and grandchild…they’d bring their friends in … sit down and have a cup of tea with Mum … it’s been a really good relationship.* CFG

It was clear from the focus group discussions that supporting the older person inevitably involved many family members. While many participants tried to protect their children from close involvement with meeting the older person’s support needs, they were expected to contribute in some way such as household chores or providing company to the older person. Many of the issues and concerns about caring for older people resonated across all six focus groups, however there were several aspects specific to the Māori group, in particular sadness at what was perceived as the loss of the ‘village’ that traditionally had provided the community support for all whānau.

The first section, *Experiences of caring for an Older Person,* provides insights into the complexities of caring for older people and the issues regarding access to formal support services to augment the informal care provided by the participant and other relatives, and the distress experienced when the responsibility is unevenly distributed among people who could contribute to the older person’s care needs. The discussions also revealed the impact of multi-generational households and relationships and attempts by the participants to demonstrate ‘caring’ to their children, involve them in the care or protect from actively supporting the older person. Nevertheless, some participants described the positive aspects and happiness that arose from caring for the older person. The second section focuses on the participants’ ideas about their own future ageing and expectations of support from state agencies and family as required by their healthcare and functional needs.
5.4 Participants’ considerations for future ageing

The second section comprises themes that emerged that related to the participants considerations for their own future ageing as influenced by their experiences of caring for an older person. There are two themes; participant’s plans and ideas for their future ageing, and prospects for support from the younger generation. Initially, when asked to discuss their ideas on their own ageing, as opposed to talking about caring for the older person, many participants found the topic very challenging. Contemplating future ageing was very difficult for most participants. Comments such as “you can’t make too many plans, because you have absolutely no idea” (CFG), or “it’s really hard to relate to being old, you just don’t feel like you’re going to be there” (CFG) typified the immediate response to questions on how the participants considered they would manage their older years. However, with encouragement many were able to reveal how they envisaged their old age would be shaped, including views on health and well-being, housing, provision of services to meet ageing needs, and prospects for provision of support from the next generation. The theme is derived from data that was coded into two categories. The first category focused on the participants’ expressed views, plans and ideas regarding their ageing, and the second concerned their stance on the involvement of younger family members in the potential support needs they may have as they age.

5.4.1 Participant’s plans and ideas for their future ageing

During the focus groups, when the topic of discussion was redirected from a focus on caring for the older person to considering participants’ own future ageing, there was resistance to such dialogue. However, with some prompting, the conversation developed as people showed more willingness to consider how they would like their older years to be managed. Often the remarks made were supported by reflections on what occurred to their older relative or friend, indicating the influence these experiences had in shaping participants’ thoughts on the future.

Anticipation of longevity
Comments from participants indicated they had considered the health and longevity of their parents as an indicator of what they could expect for their own physical well-being and life expectancy. They linked their parents’ longevity with medications to manage medical conditions and maintaining healthy eating and exercise. However, knowing how long their
parents lived was not necessarily an indication of their own life expectancy with participants indicating they simply could not predict their own future.

*I think I’m in denial – I don’t think I’m going to get old and frail – I guess I’m sort of looking at Mum and Dad and the longevity in the family and just assuming that I’ve inherited those genes so I won’t have to worry for another twenty odd years.* Clare

*A lot of people are living to a much greater age and I think it’s going to get more that way as we look after ourselves. And if your 65-70 then you can go on, it seems like you go on for so much longer than what you used to.* SFG

*If I could be as well as my mother was at 91 then it’s a goal to achieve and you sort of think - as long as you…eat healthy and you keep healthy and exercise.* SFG

One participant described the uncertainty she felt with regard to her potential longevity based on the variation in lifespan of her parents’ families. Her comment was met with affirmation by other participants equally uncertain about their future years.

*All my mother’s family lived till their 90s, but all my father’s family died before they were 70. So I’m stuck in the middle. I have no idea which model I’m on. So I’d like to move at some stage to an easier property; make sure I did have the ramps and so on, so that you’re set before you need it.* EFG

The intention of continuing to work beyond the usual retirement age of 65 years was important for another participant who indicated her plans were supported by the expectations based on the longevity of previous generations.

*My great grandmother, my grandmother, my mother, they’ve all been women that have lived to their 80s and 90s. I reckon I’m going to work till I’m 96.* SFG

**The importance of physical health and well-being**

Participants pointed to the value of maintaining general fitness and a healthy diet as a means of ensuring they did not succumb to chronic conditions that would impact on their ability to retain an independent lifestyle. When asked to describe themselves at 75 years of age, the picture they gave indicated awareness of the need to maintain good physical health but also a determination to maintain good mental health by pursuing various interests. There
Focus Group and Interview Findings

was a clear consensus among the participants of the focus groups that physical and mental health was crucial to retaining an independent lifestyle over which they had control. The following excerpts convey the sense of importance placed on this aspect of life by a range of participants.

*Fit and healthy – we all want to be that way; independent, driving, cooking, living, washing, socializing, travelling. And a lot of that, I think, it does come about by realising the modern way of living with – no fat, low carbs, and what you eat, getting your sleep, all this sort of things that we have to think about these days, exercise. So I am pretty much switched on to that.* WFG

*I would hope to keep healthy by trying to lead a healthy lifestyle and keep my mind once I retire. To keep my mind active that’s something that I think is important, to try and keep active as possible.* NFG

*Our generation now is starting to take heed of our health and saying it’s really important to keep healthy because if we keep healthy we are not going to become a liability for our children and our families, or on the health department.* SFG

*I’ve actually had a bit of a health thing in the last couple of years and I’ve lost a lot of weight and I’ve got a lot fitter and I don’t know if I was consciously thinking about my own ageing process – perhaps it was part of it but I just think – well there’s actually so much to live for, there’s so much to do.* SFG

**Maintaining mental health and cognitive functioning**

Participants also recognised that physical health alone is not enough in maintaining overall wellbeing as a person ages with reference to the significance of maintain independence and keeping their minds active too.

*You need to prepare yourself with a range of interests that don’t depend upon the family, or depend on you being hugely active. You might be rambler now, or with the joggers, but you need to have a range of intellectual interests that you can pursue as well.* CFG

*Just really trying to be as independent as you can, obviously, and still have the interests and your mind ticking over too.* NFG
Focus Group and Interview Findings

**Housing preferences**

Another area of particular interest to the participants was the type and location of the home they would wish to live in as they grow older. A few participants had already begun to consider their housing preferences and spoke of ‘down-sizing’ or moving into a low maintenance property. Several participants also indicated a desire to live near to family while retaining their independence; even if their home was a unit in a retirement village. There were comments on the actions of the older people they had cared for which indicated there had been no planning for the effects of ageing and no decision to move into more suitable accommodation resulting in difficulties for both the older person and the family member providing support. Some participants indicated they intended to relocate into a more suitable home before they reached the stage of becoming too old and frail to adapt to the necessary changes.

*Because of what we’ve been going through with my mother, seeing her go down to a smaller place at 87 – she only had two years there. She left it too late. I would be wanting to make that last move…in time to actually establish myself and establish, perhaps, new friends in a different area… and enter new communities and make new interests.* EFG

*Moving into a smaller house, once you don’t have the responsibility that you have [with children] because we have quite a large house at the moment – so something smaller and more manageable and a dog to keep me company to walk because that kind of keeps me physically fit.* NFG

*When I bought this house I was on my own and I did think of not driving – I’m near [supermarket] and I can get a bus to [the shops]. I can live on one level, it is two storey but there’s a bedroom and ensuite downstairs – I wouldn’t need to go upstairs. Fairly flat, good street, easy walk to town. I did think of those things if I was going to be on my own.* EFG

A few participants had already begun to plan for their older years with ideas on the type of home they thought would be suitable to the expected age-related needs. The following excerpt illustrates the influence of participant’s profession as an Occupational Therapist on the most suitable housing for her older years.
Focus Group and Interview Findings

We’ve actually put a lot of thought into it – I have because of my OT background – so I don’t want stairs – I want brick and tile…aluminium joinery, easy care, flat section – I know what I want. SFG

Another participant preferred the option of living close to her family in a small house but also retaining some independence and personal space.

I think the ideal arrangement would be if you had a granny flat so that everyone did have their own space a bit more. CFG

However, not all participants envisaged a single level, simpler style of home. One participant displayed admiration for her older neighbour who continued to live independently in a multi-level home, and expressed a desire to emulate the older woman.

The old neighbour and her children are like, they’re family. She is 90…and she is still driving and still involved with people, and exactly the way I’d like to be. She lives in a two-storey house with a circular staircase and she has her strategies for getting up and down and making sure she is safe. EFG

Co-habitating with friends or siblings

Participants who currently lived alone or anticipated the possibility of being widowed due to their partners ill health, suggested they were interested in either a ‘flatting’ type arrangement where they would live with friends or certainly living in close proximity to people of similar age and providing support to each other. Participants who had past experience of ‘flatting’ when young suggested that, unlike their parents’ generation, they could adapt to a similar living situation should the need arise.

I have discussed this issue [housing] with my friends – and if C [husband] was to die a lot earlier than me, which is on the cards with his age and health, then we have discussed the fact that we would go flatting together – I have a friend who is single, who would be quite keen to do that. Anne

We haven’t made specific plans but the general thing amongst friends, and I don’t have any children, is that we will buy a flat together, in a row, try and at least be near each other, so that we are not lonely. NFG
Focus Group and Interview Findings

I come from a large family and my sisters and I said we will probably do something like – share a house. I have heard of two women who have done that…they’ve got their own areas but they’ve combined their funds. So I think that’s quite a good idea.

NFG

Communal housing and retirement villages

One participant spoke of a charitable organisation originating in the UK that aimed to facilitate the accommodation for socially disadvantaged older people, which she saw as a positive alternative to living alone.

[The] Trust, which is shared flatting with older people but with a trust kind of overseeing - so they manage the finances, there’s a housekeeper that comes in to cook the meals you want. So it’s independent living but with company…I could imagine a similar kind of set up but with my friends, rather than a formal outfit. EFG

An aspect of housing and, in particular, the retirement village option was of concern for many participants from either the financial perspective or the standard of support offered by such facilities.

There are a lot more retirement home options aren’t there? And what I do find interesting, I mean there are lots of rest homes with hospital level care, but the standards are very variable. CFG

There’s a lot of retirement villages in New Zealand where people can go and they’re not lonely. A lot of people don’t like that idea; you’ve got to look at how these retirement homes are set up…but I think there are good rest homes and there are bad ones. NFG

One of the concerns discussed regarding living in a retirement village was loss of the usual community demographic of mixed ages and the inevitability of seeing people ageing and dying. Participants observed such a situation as being depressing.

One couple, there was quite a difference in the age between the husband and wife, and the wife got quite depressed, there were so many people dying around her. Constantly in that environment, not a mixed environment of old and young. EFG
My aunt was in a rest home and my mother said to her, do you have any friends here, and she said “Oh I did have a friend, but now I don't have a friend because they all die” And it can be quite depressing. EFG

In referring to the awful experience her mother had with rest home care, another participant commented on her own future, saying “I just never would want to go into care. Not from the experience I had with my mother” (NFG). Her views were similar to a participant whose feelings about ageing and dependence were so strong that she indicated a preference for dying rather than the possibility of living in a residential care facility.

I'm not going to a retirement village. If the time comes where I'm honestly aware I'm losing my marbles I'm disappearing and you won't find me. I'll tell someone where I'm going eventually so they find the body but apart from that I'm not going to live long enough to be demented in a retirement village. SFG

An interviewee commented on the possibility of being in residential care after discussing her experiences of having her father live with her until his death from cancer, saying;

I don’t know whether it’s the nursing background and it's certainly nothing to do with my Dad dying, - I do not want to ever end up in a rest home - that does not appeal at all. I've never thought that's really quality of life that I would ever want to, by choice, have to move into. Jenny

In contrast, one participant had the experience of looking at a particular retirement village and talked of the positive aspects of living in such a community. She expressed the view that she would be comfortable with the style of living offered in such a setting. Another participant had a similar experience with the facility her mother had resided in which provided a stimulating environment; one which she could envisage living in herself.

One day I went on a historical trip...And we went through the village that's by the town there, and they say a third of [the local people] move into that village...And they get to know each other and a complex like that it seemed very happy. We had a look through … it was wonderful. We went through the craft village - they make crafts for the shop. And they have a hall, they have functions on, and it's just a real country town wonderful surroundings… it was just lovely. So I'd quite like to go into
somewhere like that, and get myself established, when I decide to move from the house I'm in. EFG

Ordinary, straight rest home run by a trust with a complete occupational therapy and complete physiotherapy staff there all week, programmes, activities, buses to take them out. It's a really good home. I would have no fear about going into a place like that. EFG

A participant, whose mother currently resided with her as she has both physical and cognitive impairments, expressed the view that she and her husband would like to shift into a retirement village. Her reasoning included the view that she did not want to be cared for by her children.

We just thought – say in 10 years, when we’re say 70, we thought we’d both like to go into a retirement village and go from there. Rather than be looked after by our children which I don't think is a good idea anyway. NFG

The opinion conveyed in the last excerpt was shared by many other participants across the focus groups. Conversely, many focus group participants and interviewees also indicated a desire to live near their families with the possibility of accepting support from their adult children as they aged. There was also talk of relying on the government to provide aged-care housing or assistance. The last category focuses on the views and expectations of the participants, as current mid-life adults, regarding their determination to avoid being a burden to their children or other younger relatives or the potential for support they may expect from them.

5.4.2 Prospects of support from the younger generation

Research reveals the prevalence of relatives, particularly the subsequent generation, being the key people in providing support and functional assistance to older people as their ability to maintain independence diminishes. For this reason, a question regarding participants’ views and their expectations of succeeding generations for support was included for the discussion in the focus groups (see Appendix 12). The participants were asked about the involvement of their children or younger family members in the care or support of the older person, generally a grandparent, and to identify the person or people the participant thought would be most likely to provide them with the support they might require in their older years.
Companionship from grandchildren

One aspect of the younger generations' relationship with the older person that proved positive and was welcomed by both the older person and the adult carer was that of companionship. Such interaction was especially evident in the multi-generational household with close proximity fostering the opportunity to communicate.

_Dad loved the young company…he loved the kids around. He got a bit less patient in the last few years as he got deafer…but earlier on they were really good. They’d laugh and carry on. Dad, particularly, liked spending time with A [granddaughter] and when her girlfriends came around he’d joke with them. I think he probably – yeah, he would have spent more time talking with A, probably, than B [grandson]. Clare_

Talking about the experiences of her family in providing the care and support her father needed in the last weeks of his life, Jenny described how each of her children had a different but special relationship with their grandfather. Jenny regarded this time as ‘special’ and a treasured part of their family history.

She [daughter] was very gentle and loving and really good and our eldest boy had all his friends around, so they would come in and talk and you know [saying] “Hi Granddad, how are you?” And go in and sit with him and things like that. And then out middle one is the one who would often just go in around twilight and just sit and play – he’s a very good musician. He would just play his guitar and sit there playing and lost in his own little world. Jenny

Modelling the caregiving role

Several participants talked of how their children were aware of the support they provided to older relatives and in some cases had witnessed the extent and nature of the assistance given. Some participants indicated that they were consciously ‘modelling’ their behaviour in front of their children and an indication of how their family has supported each other across the generations. One interviewee acknowledging the difficulties associated with caring for the older person were plainly evident to the younger people, but hoped their children saw the positive commitment to caring for family members.

_ I guess they [grandchildren] saw that it's quite a commitment. It's quite a bit of hard work, I mean not just physically but emotionally to do all of that. But I guess they saw that…when you love and respect someone that you're prepared to do that. And that, I_
guess I tried to demonstrate to them that, you know, my dad was wonderful and had always been there for me. I didn't feel this was a burden on me. I would have done it a hundred times, you know? And it seemed very normal to me and we were really, really close. So I hope I modelled that for the kids that you know, I said to them, watch very closely because if there ever happens to us perhaps you need to do this for us. Jenny

They reckon that 40 percent of our behaviour now is actually modelled on the behaviour of our parents, not necessarily their genetic trait in a sense. WFG

In contrast to the participants who reported modelling their caring behaviours, many others were adamant they did not want to become a burden to their children or younger family members should they require assistance in the future.

My daughter’s seen what I’ve been going through and she really feels it as well. She’s really worried about her nana and she said “Don’t worry Mum I’ll look after you when you’re older”. I said “No you can’t, I wouldn’t want to put you through this”. I said “Shoot me if I get like that”. SFG

Recogniton of potential conflicting responsibilities for adult children

Another issue identified in relation to family support was the likelihood for participants’ adult children to travel and settle in other parts of New Zealand or abroad making them unavailable to provide practical support to ageing parents.

Most of our children are overseas and I can’t see my daughter coming back. She’d go to Australia rather than here, there’s no future here. EFG

There was also the reality of the adult child’s own responsibilities and how this would make them less able to assist the participants' with their needs.

You’ve got to look at your children – I’ve got a daughter whose 40 and she’s got little children, they’re pre-school, one goes to school…they’re getting older having children – we were in our 20’s. That can impact a lot on their support of you. NFG

If my children were not in a position because they both had to keep working, and their spouses were working, then that would be the way it is. Anne
One interviewee joked about the exchange she and her husband had had with their children on the prospects of them providing support in the future. These comments, made in jest, indicated a sense of not being able to rely on support provision.

\[\text{We've said you know, we expect you to look after us and they've said no way, we'll put you away as soon as we can. Clare}\]

While aware their children had seen their care provisions for older relatives other participants were quite clear they did not expect the same response from these children in the future.

\[\text{We'd never intentionally made our children feel that one of them had to step in and do what we have done for our parents or what I've done for my mum with my husband's help. I think I'd much rather be independent – I wouldn't expect them to do it. SFG}\]

**Participants’ desire not to be a burden to their adult children**

In recognition of their experience of caring for an older person and the inherent demands of the caregiver role, it was clear from participants comments and discussion that they did not want to burden their adult children.

\[\text{I wouldn't want to put this on my kids. I just wouldn't want to do that…I feel that we've done the right thing looking after my Mum – I wouldn't want to put her into care, not unless it really got to the stage where we couldn't manage. But I wouldn't want to put my kids through this, but who knows what the future holds. NFG}\]

\[\text{You’ve seen what you’ve done [for parents] and you think “Gosh, would I want my children to do this for me?” No, probably not but I would quite like to live close so if I knew I needed anything they were there. SFG}\]
**Expectations of government-funded support services**

Nonetheless, when asked to indicate who would support their aged-care needs, if not their family members, participants were clear regarding their expectations of the ‘state’ to provide. These expectations were linked to the knowledge of insufficient personal finances to fund private care, but also to the implied social contract with the government based on taxes paid during their adult working life.

*Well the basic solution for me would be the state. If I was in a situation where I couldn’t afford to or if I could afford to I would probably go in a private situation. I think a lot of the way you structure your life, and the way you think, is based on how you have run through the years yourself. It’s quite easy for me to turn around and say well I’ve worked all my life, and paid my taxes, you know now it’s time to get a little bit back or something. There’s that approach. But I’m not that sort of state minded that, you know if I was reasonably well off and I could afford to have private nurse care, I would have it.* WFG

*If I had to rely on, to be quite cutting and candid about it, if I had to rely on anybody, I’d want to rely on the state.* WFG

**Hopeful expectations of future support from adult children**

In spite of a determination to not be a burden to their children, there was also an element of hope; with one participant saying the future is uncertain in terms of what they might need or expect from their children. While these participants were clear about their expectations of the government to provide for their needs it was apparent that they still harboured hopes that their family may be prepared to support them, should this be needed when they grew older.

*I could see me living with one of my children. But I also have to look at the circumstances, because they’re all living at home. I’d have to look at their circumstances and they would be older and maybe have their own families.* WFG

*I suspect when, if and when we ever needed support they would give it. But I certainly would not demand it of them. If they were able to give it, and were happy to do so, then I would be happy to accept it.* Anne
Focus Group and Interview Findings

I would hope that one of them would take on that role. I mean when things got close to the end with my mum, the oldest one [grandson] suddenly took on a role I never expected. He took on a role of support, making decisions to help me out. And it was quite a surprise. So he may, but you see we don't know. WFG

I don’t think our children should have to look after us anyway really. I mean it would be nice if they had something on the end of their property – like a unit or something – we’d be happy to do that if they’d let us. NFG

For some participants there was a clear expectation that their children would support them in the older years as a form of reciprocity for the care they had provided to these younger family members over the years.

I've got a son… and a daughter, that’s the single girl. And [another] son…and I see them all. I’m very fortunate. Because I was a solo mum for thirteen years, I think they realise I sacrificed my life for them for many years and they appreciate what I did for them. So it’s paid back. But they’re great. .EFG

Well the way things, I've seen at the moment, if it stays the same, you'd rely on your family more so than anything to help you. WFG

The final comment comes from the interview with Jenny who talked about her family experience of caring for her father when he was dying and the impact this had on her family. She talked of how her father’s last weeks, lived in her home, gave her children a valuable experience on the importance of relationships and how supporting each other was part of family life. The following excerpt demonstrates many of the views expressed by other participants; the wish not to be a burden but the hope of receiving support from their children.

I don’t want to be a burden to my kids but I don’t want them to ignore me or neglect me or leave me to my own devices or just swan off with their own lives…maybe I hope I’ve been a mother where they’ll want to support me into my old age, you know, that sort of thing. Where they won't do it because they have to - they really want to do it and it works for everyone. Jenny
Focus Group and Interview Findings

While participants acknowledged that maintaining physical and mental health were important considerations for ageing, many were in denial about the inevitability of their own future ageing and how their age-related needs might be met. There were many comments from participants wanting to avoid burdening the younger generation with their ageing needs, even while many participants expressed the hope of living close to family and the possibility of receiving support as they aged.

Conclusion

Chapter five summarises findings from the six focus groups and five individual interviews. The themes that emerged from analysis of the data reveal how experiences of caring for or providing some form of support to an older person has shaped the thinking of the participants in relation to how they envisage their own older years, and the prospects of receiving support from younger family members for their own age-related care needs.

The first theme of *Experiences of supporting and caring for an older person* provided an in-depth view of the multi-faceted experience of caring for an older person and how this has impacted on all the family members. Participants revealed concerns about the loss of respect and negative attitudes toward older people from others in society, especially views that saw the older person as a commodity. Supporting the independently-living older person presented concerns regarding the older person’s functional capacity and safety as well as the need for increasing support. For many participants accessing appropriate support services proved very difficult, although those provided by ACC or for palliative care were well regarded. Nevertheless, the increasing need for support caused stress for many participants as they faced conflicting demands from family, partners and employers additional to the older person. Some families worked together to support each other and the older person but several participants revealed frustration with the limited support offered by siblings resulting in considerable family discord. Nevertheless, some participants spoke of positively of their experiences in caring for an older person, particularly the Māori participants. However, the perspectives shared by Māori participants uncovered the difficulties they experienced both in terms of caring for their older relatives and also the loss of the cultural models valued by their elders. Participants spoke of the older person’s hospital admission and the lack of consideration from some hospital personnel.

The second theme of *The multi-generational household and family relationships* focused on the very personal aspects of interdependency between family members and various
Focus Group and Interview Findings

supports offered. The circumstances leading to multi-generational living arrangement varied considerably with duration in cohabitation from a mere six weeks to more than 20 years. Relationships in the multi-generational household were both positive and negative with the key to success being tolerance and family acceptance. Most participants attempted to shield their children from involvement in caring for the older person but there was evidence that some grandchildren participated in the care needs of the grandparents such as helping with home-based dialysis treatment or providing companionship.

The second section focused on participants’ considerations for future ageing and detailed reflections shared by participants on their plans, hopes and expectations regarding their own future older years. Expressions of denial about the prospect of ageing were common but participants also stressed the importance of health and fitness to retaining an independent lifestyle. Although a few participants had begun to plan for the future, many eschewed the options of retirement village living, preferring to live independently. Comments also shed light on how these people view the prospects of their aged care needs being met by government funding and family. The prospect of receiving support from the younger generation held few expectations and was met with a determination not to burden these family members. However, many participants did proffer the idea of living close to family and the hope that their adult children would be able to support them should the need arise in the future.

The categories that make up the major themes were utilised to inform a survey questionnaire, the details of which are described in chapter seven. The following chapter provides a deeper exploration of the experiences of five individuals drawn from the focus groups participants. Each interviewee shared their story of caring for an older person and also the intergenerational caring evident in the families.
Chapter 6

Insights into the complexity of aged care through family stories

Sharing the experience of Dad’s last weeks and him dying in our home has become a significant part of the tapestry of our family history. Jenny

Introduction

The purpose of including the following five family stories is to provide insights into the experiences of a small selection of participants and their reflections on how these events have shaped their ideas of future ageing. Each person who shared their ‘story’ had previously participated in one of the focus groups. All focus group participants were offered the choice of participating in an individual interview and could indicate their option on the consent form (see Appendix 7). The five people chosen for an interview were selected on the basis of having quite diverse experiences as revealed during the focus groups. It was considered that such diversity would contribute to greater understanding of how people coped in practical, psychological, emotional and economic terms with ageing relatives’ needs and how these factors impacted on their own life. The stories also drew out many of the intergenerational features; from the influences on participants’ perceptions of parents and grandparents ageing to expectations of their own children or younger relatives. These features are depicted in family trees covering four generations of the participants’ family which illustrate intergenerational caring. Reflections on the prospect of future ageing and ideas of how each participant envisage their older years are also presented. Each interviewee chose their own pseudonym and had the opportunity of reviewing their stories and making any changes they considered appropriate. None of the interviewees’ relatives have been mentioned by name, instead family titles such as ‘Grandma’ or ‘Grandpa’ have been used.
6.1 Clare’s family story

Events that change your life significantly are often unexpected. Such was the aftermath of the accident Clare’s mother experienced in her garden. Clare’s parents’ lives were changed irrevocably and as a consequence she and her siblings faced the prospect of their mother’s disabilities and father’s struggle to cope with these changes. However, to put their response to this event in the context of intergenerational relationships and caring, it is important to consider Clare’s recollections of her grandparents older years and how the family supported them as they aged.

Clare has distinct memories of three of her grandparents as they all lived long lives, but her paternal grandfather died in his twenties. Clare’s paternal grandmother, “Grandma”, widowed by the war, lived in her own home with her daughter and granddaughter. Clare recalls visiting her Grandma, aunt and cousin every Sunday. She was quite a stern woman but they got along well and would play cards and enjoy jokes, although Clare’s brothers and sister were a little scared of her. Clare’s memory of this period of her grandmother’s life was that she was quite independent and capable, although, increasingly her aunt took responsibility for the cooking and other household chores. Grandma maintained quite good physical and mental health until her sudden death from a brain haemorrhage at the age of 89.

Grandpa, Clare’s maternal grandfather, developed circulation problems resulting in both legs being amputated. However, he continued to live at home, being cared for by Clare’s grandmother and uncles until his death. Clare was young when her Grandpa died and cannot recall the specific details of how he was cared for at home, but presumes her uncles helped to lift their father in and out of his wheelchair as needed. Clare’s Nana lived alone for many years after her husband died and Clare recalls weekly visits. When she became increasingly frail, Nana went to live with Clare’s parents. Initially she was able to care for herself with Clare’s mother providing meals and cleaning. However, in the last few months of her life Nana suffered from heart failure and had some minor strokes. She moved into a rest home, where she was bedridden until her death at 95 years of age. Clare recalls her mother expressing feelings of guilt about her Nana being in the rest home and not being able to care for her at home.

Clare’s parents retired at a relatively young age after a busy life running a family-owned business in a rural town; her father was about 63 and her mother 57 years old. They really
enjoyed their house and garden, and also enjoyed travelling around the country in their caravan visiting family. With two sons and two daughters they had many places to visit and grandchildren to keep up with. Aside from her mother’s heart bypass surgery and her father’s bowel cancer, Clare considered her parents were leading an active, happy retirement. She thought these years were justly deserved after the hard work and long hours associated with running the business.

The day that changed their lives unfolded like any other with Clare’s mother taking a kitchen knife with her to the garden to pick vegetables for their lunch. Clare’s father went to investigate after some time had passed and she had not returned from the garden. He found his wife lying unconscious on the ground. The exact circumstances of her mother’s accident remain unknown, although she may have tripped and fallen. At first, it was thought that she had suffered a stroke or heart attack, however the detective work of their neighbour, who was also an ambulance officer, lead to the discovery that the blade of the knife had entered her brain. The only outward evidence was a small scratch near her eye as the handle had snapped off in the accident. Clare’s mother was transferred to a major hospital for urgent neurosurgery. Initially, it was uncertain whether she would survive the trauma of the accident and surgery, but she did with the resulting effects being similar to a severe stroke.

After many months of rehabilitation in the hospital, Clare’s mother eventually returned home. The previous roles of the couple had reversed with Clare’s father being the carer and her mother being cared-for. Clare acknowledges the invaluable support of the ACC for providing a variety of services, such as cooking, cleaning and personal care for her mother. To start with she could get about with a ‘quad-stick’ and a belt for a helper to hold onto but later she progressed to needing a wheelchair. Clare recalls her parents coping reasonably well with these dramatic changes, although her mother was frustrated at no longer being able to pursue her interests in gardening, cooking and handcrafts. While they found the role changes really hard they did adjust quite well. Her mother also exhibited some personality changes after the accident, typical of a head injury, which they found difficult to cope with as they had not been informed of such effects. Over time these behaviours decreased and her mother returned to being more like the person they knew.

Clare’s parents continued to travel, with many trips to stay with the family. Clare learnt to manage their mother’s physical needs, especially personal care and dressing, although Clare felt her mother did not really trust her or her sister to shower her, preferring the support of her ‘proper’ carer. Her parents even managed to fly south several times to visit her
brothers, and all siblings would stay with their parents from time to time. When Clare’s parents visited her brothers, they would arrange for a local support service to assist their mother with showering and dressing. Otherwise her brothers’ role was confined to entertaining and cooking. The brothers would also stay with their parents for short periods but again support did not involve any personal care of their mother. There are several grandchildren in the family, and Clare’s children were living at home during their grandparents’ frequent visits after their Nana’s accident. Clare recalls her daughter and son both socialising with their grandparents and occasionally assisting their Nana with some of her physical needs.

As the years went on, Clare and her sister noticed the increasing needs of their mother was placing a heavy burden on their father’s health. Their father was becoming exhausted, unwell and miserable. Clare’s mother had always been resistant to the idea of moving into a retirement village, possibly due to her feelings regarding her own mother’s placement in residential care. Whenever Clare and her sister broached the subject of their mother’s increasing care needs, her parents would call their sons, complaining that “the girls want to put them into care”. Clare reported her brothers were very aware of their parents’ situation and supportive of their sisters. Eventually, on a visit to Clare’s sister, their father became ill. Clare’s mother finally agreed to enter a rest home for a period of carer respite and this change became permanent with her father living with Clare’s sister, close to the rest home which enabled frequent visits. Initially, Clare’s father’s health improved without the physical demands of caring for her mother, but after her mother died his health deteriorated quite quickly. He agreed to move into a rest home but this was only for a short time as he developed a bowel obstruction and died quite suddenly aged 96 years old.

While she could never have envisaged the accident that befell her mother, under no circumstances did Clare regard the care and support she offered her parents as an obligation. She said she simply made the best of the situation and got on with helping them as needed. Clare acknowledges the generosity and support of her sister and brother-in-law in providing their father with a home during the last two years of his life.
Clare’s reflections on future ageing

Longevity is a feature of Clare’s family and she hopes she has inherited these genes. She recalls her father’s comment when he was about 93 years old of forgetting how old he was and thinking he was only eighty. She says he always associated with younger people and never thought of himself as old. Clare sees herself as being like to her father and assumes that 30 years on she will be doing similar things to what she is doing now.

At present, Clare is in her early sixties and employed full-time. Clare firmly believes she is not going to get old and frail, freely admitting that she is in denial. She is planning a long and happy retirement and hopes she and her husband can maintain their current good health. They have plans to complete the renovation of their home and to travel around the world. She joked that she and her husband have told their children they expect them to care for them in their old age. She cannot imagine living with her own children and would not want to be a burden to them, but does have the wish is that she will live near her children and is comfortable with thought of them offering her support as they are able. Clare concedes that she may not have the financial resources to provide for her own care needs and has an expectation of some form of support from government services.
Maternal Grandmother died at 94 years. Lived with son & his wife. Reasonably independent until health deteriorated then moved into a Rest Home for last two months.

Maternal Grandfather died at the age of 72. Had circulation problems & was a bilateral amputee. Cared for by his wife and sons.

Paternal grandfather died in his 20’s.

Paternal Grandmother died at 89 years. Lived with her daughter & granddaughter. Independent until she suffered a brain haemorrhage.

Mother died at 88 years with her last years spent in a Rest Home. Incapacitated after an accident at 73 years.

Father died at 96 years of Bowel Cancer. He was active in supporting his wife until her death then lived with a daughter (not Clare) but moved into a Rest Home just before his death.

Clare. Parents lived 1 ½ hours drive away and stayed with her occasionally. Assisted with showering, toileting & dressing mother as needed.

Brother. Lives in South Island. Would stay with parents twice a year. No practical assistance but emotional support.

Sister. Lives 1 hour drive from parents. Occasional practical but more social support. Father lived with her for 1 year before dying.

Brother. Lives in South Island. Had parents stay with him but arranged for nurses to provide care for mother in the house.

Daughter. Aged 13-20 years when grandmother needed support. Provided some practical/social support.

Son. Aged 11-18 years when Grandmother needed support.
6.2 Jenny’s family story

Critical events can occur in a family that affect all involved. Jenny’s father’s last weeks of life were spent in her home, surrounded by all the activities of normal family life. Grandchildren and their friends came and went, frequently spending time with their grandfather. Jenny considered the experience of her father dying in the family home, shared by his son-in-law, grandchildren and herself has become an important part of their family history.

Jenny believes being a nurse was the factor that enabled her cope with her father dying in her home. However, the decision to have her father move into her home was not taken lightly. She described discussing the possibility of Granddad needing more support with her husband and three children. Jenny and her husband had already discussed their concerns regarding ageing parents but wanted to include their children in the decision. She offered each child a choice of whether or not to have Granddad stay, acknowledging it was their home and sacrifices would need to be made. Jenny reports her two sons’ and daughter’s response was immediate; that Granddad would come to stay.

Jenny and her older sister were adopted and raised in a close-knit family. She has met her birth mother, whom she resembles in many ways, however, Jenny was particularly close to her adoptive parents. Of Jenny’s adoptive grandparents, only her paternal grandmother was alive when Jenny was growing up. Grandma was already very frail when she moved into a rest home near Jenny’s home and died when Jenny was just six years old. Visiting her Grandma in an institution filled with older people and the smell of cooked cabbage remain strong in Jenny’s memories.

When Jenny’s mother was just 63 years she chose to move into a rest home. Jenny’s mother developed Rheumatoid Arthritis in her mid-forties and quickly became crippled by the condition. She lived in the rest home for 15 years, and Jenny’s father and sister visited frequently until her death at the age of 78. By this time Jenny, her husband and children were living overseas with occasional visits home. When Jenny and her family returned to live in New Zealand, their grandfather was a less familiar person in the lives of the children, then aged about 13, 12 and 10 years old. Living relatively close now allowed them the opportunity to get to know their Granddad better. Still living in the home Jenny and her sister were raised in Granddad was keen to maintain his independence and led an active life. He enjoyed having family nearby and got along well with Jenny’s husband. This good relationship proved
beneficial later when Granddad moved into Jenny's home and her husband was able to offer his father-in-law considerable practical support and company.

Some years after their return to New Zealand, Jenny's father made the sudden decision to move into a smaller unit closer to Jenny and her sister. Jenny reflected that in hindsight, her father’s health may have been deteriorating slowly at this time but they chose not to see these insidious changes, considering they were probably part of normal ageing. The unit was warm and sunny, and he continued to be active; driving, cooking, working in his garage, and maintaining his home. Not until her father attended his general practitioner with acute gout did his health issues became evident with a blood test revealing the development of myeloid leukaemia. The treatment plan included repeated blood transfusions with Jenny and her sister supporting their father throughout this time. The pattern of treatment and tests continued for three months before the unexpected change to a more aggressive form of the condition with a prognosis of six weeks to live. Although Jenny’s father was very stoic about the diagnosis, it was a tremendous shock for Jenny, her sister and their families. After a short hospital admission, Jenny’s father moved into her home and remained there until he died six weeks later, just short of his 90th birthday.

Jenny believed the nature of the relationship with a person, prior to an event, such as the revelation of her father’s incurable diagnosis, determined the choices made and how to best support that person. Although Jenny’s mother and Grandmother had both died in a rest home, she was determined her father would not move into such a facility nor a hospice, believing her nursing skills and the support of the community palliative care team would meet his continuing physical needs. Jenny never thought of her father as a burden and the family would not consider any alternative other than him staying in their home. Jenny was very pleased her husband and children were unified in their choice of having their father-in-law and Granddad live with them for the last weeks of his life. She also acknowledges the “wonderful” support her husband provided both her and her father, and the palliative care team who not only cared for her father but also the family. Jenny’s sister and her husband would visit often during the last weeks of their father’s life. For the sisters there was the uncertainty of how long their father would live, how his needs might change, how this would impact on the family, and how they would cope individually and together.

Some changes did occur to accommodate Granddad, with Jenny’s daughter giving up her room and a hospital bed being acquired when he became bedridden. Each of the grandchildren spent time with their Granddad in different ways. Jenny describes her
daughter as very gentle and loving, encouraging her Granddad to eat chocolate with her while they watched television together, or fetch his meals and clean his teeth. The oldest grandson would often sit and talk to Granddad, while the younger grandson would gently play his guitar. Jenny describes this period of time as rewarding, emotional, exhausting, and very, very special.

Reflecting on the impact of her father's ageing, illness, dying and death, Jenny believed her children would have seen the commitment, hard work, love and respect she, her sister and their husbands offered this much loved father and grandfather. Jenny commented that her father was “wonderful” and supportive, and she hoped her children recognised she was reciprocating his commitment to his family. She is optimistic that seeing her and her husband caring for their grandfather over his last years and weeks of his life had offered her children a good model of normal family love and caring.

**Jenny’s reflections on future ageing**

In her mid-forties, Jenny has, potentially, a long working life ahead of her. She is very active and healthy, enjoys socialising and has many interests. She and her husband have moved several times and she believes they can make a home anywhere; however they see New Zealand as their retirement destination. The couple have talked a lot about what they want to do in terms of work and retirement in the future, and the type of lifestyle they would like to lead as they grow older. They may consider travelling and working overseas in the future, when the children have completed their education and are independent.

Jenny talked of finding accommodation with suitable access supports. She and her husband have discussed the possibility of moving into a retirement village or an apartment at an early age. Her current occupation as public liaison for a rest home has put her in contact with older people considering a change of housing. Many of these people have no children, siblings or younger relatives to support them. However, she is concerned about the limited outlook and quality of life many rest homes offer the residents.

Jenny perceived her generation as one brought up to accept the “user pays” philosophy, therefore has limited expectations of government funded services to support her in old age. She does not want to be a burden to her own children, but does hope they will not neglect her when she is older and that they would want to support her into old age.
Jenny’s Family Tree

Adoptive maternal Grandmother.
Died aged 78. Lived alone in family home after husband died with support from family living nearby.

Adoptive maternal Grandfather.
Lived in family home with wife and family support.

Adoptive paternal Grandmother.
Died when Jenny was 6 years old. Lived a distance from family and moved into a Rest Home when she needed increased support.

Adoptive paternal Grandfather.
Died of cancer at home cared for by his wife.

Adoptive Mother.
Developed severe Rheumatoid Arthritis. Lived in a Rest Home for 15 years before dying at 78 years of age.

Adoptive Father.
Died aged 89 years of Leukaemia. Lived with Jenny for 6 weeks before his death. Previously lived independently.

Sister.
In denial about father’s illness. Had him stay for weekends in her home toward the end of his life.

Jenny.
Good relationship with father. Took him to medical appointments and assisted with help at home as he became unwell. Provided homecare for the last 6 weeks of his life.

Son aged 20 years.
Involved with friends but provided social support of grandfather when he lived with the family.

Son aged 19 years.
Provided companionship toward grandfather.

Daughter aged 17 years.
Provided practical support and company to her grandfather.
6.3 Anne’s family story

Caring for an ailing spouse or partner can be challenging for the more able member of the partnership. When the caregiver develops an illness, the balance changes and may never recover. Such was the situation with Anne’s parents. Her mother’s physical needs had been met by her able father until his own sudden illness resulted in a precarious situation for them both. Anne’s parents had moved into a retirement village when they were both in their eighties, a decision that allowed them to maintain their independence but brought them closer to Anne and her sister. At the time of the move Anne’s mother had been suffering from chronic obstructive pulmonary disease for about eight years. Her father was quite fit and healthy, still playing tennis and driving. Together the couple managed their daily activities quite well and Anne and her siblings had a “hands off” approach, assisting their parents only when asked.

When Anne’s father became ill very quickly with three lengthy hospital admissions with bowel disease over a period of six months her mother managed at home with increasing support from the family and some help through aged care services. However, the biggest impact on the family came when their father’s development of dementia. At first it was thought that his memory issues would be temporary; an acute delirium associated with his physical illness. Anne described how her father, who despite his memory loss could still drive under the direction of her mother who had never driven; a situation that caused great anxiety among the family members. The couple struggled on until a series of illnesses brought about her mother’s death and the focus of family concern turned to her father.

Anne reports her father is lonely, as, when she was alive, Anne’s mother had initiated social contact for the couple. Since her death, Anne’s father relies on the family to motivate him to participate in family activities, and also transport him to appointments. Although his isolation is of concern to the family, they are even more worried about their father eating regularly and looking after his personal care. Maintaining his physical condition requires prescribed medications; a regime the family are uncertain he is following. The overall anxiety centres on his variable memory and lack of motivation to be responsible for his own needs, which, no doubt are aspects of his dementia.

Anne has four siblings and together they have worked out how to support their father to ensure he maintains a semblance of independence within the restrictions of his physical and mental health. Anne describes herself as the ‘practical one’ and, together with a sister who
lives nearby, provides daily support, such as meals, shopping, changing linen, washing, and driving her father to hospital appointments. She also telephones her father frequently to remind him to take his medications or generally feel reassured that he is safe. While the siblings’ support role has ‘evolved’ as their father’s needs have grown there remains the gnawing anxiety about the future and how they will cope as their father’s health issues continue to manifest and his needs increase. While her father has expressed an interest in moving into a rest home, at this time he is ineligible as he is still functioning too highly to meet the entry criteria.

Anne has enjoyed a very good relationship with both her parents, reporting how supportive they were at various points in her life, giving emotional and practical help when needed. She has few memories of family support of older relatives due to immigrating to New Zealand as a seven year old, but she considered her parents willingness to assist and commit to their children was part of their family ethic and something she carries within her.

**Anne’s reflections on future ageing**

As a health professional, Anne is very aware of the physical changes related to ageing. Prior to her parents’ illnesses and mother’s death, Anne and her husband had mapped out their own retirement. Currently they live in a multi-level home on a large section which has been ideal for their family of three children. Anne’s husband plans to retire in the near future and his own health issues mean the family property is becoming more difficult to maintain. They had planned to move into a single level, low-maintenance house with practical features, such as a walk-in shower, and a small easy-care garden. However, responsibility for her father’s day-to-day care will remain with Anne and one sister which makes plans for the future uncertain. Her brothers and youngest sister have their own responsibilities which preclude them from providing regular practical support. She even envisages the possibility of a self-contained flat attached to her home where her father can live independently, but with close supervision with meals and medications.

At this time Anne’s children are still relatively young and at the stage of developing their own careers. They are all living at home; a factor which Anne and her husband anticipate will change as their sons and daughter complete their education and job training and take the opportunity to travel. She reports having discussed issues of ageing with friends with the idea having emerged that if they ever found themselves living alone they would explore the possibility of ‘mixed-flatting’, which they had experienced during their pre-marriage days.
Another possibility is to shift into a retirement village, similar to the one her parents moved to, but with staged care catering for a range of age-care needs. Anne expressed the view that she would want to look around and choose her future accommodation while still capable of making decisions, rather than let circumstances force her to opt for a less desirable place. However, she acknowledged that the retirement village option would be costly and she would prefer to be in an independent home.

When Anne’s parents needed greater support from her, she spoke to her children, requesting they contribute more support with running the home, thereby freeing Anne to attend to their grandparents. At this stage in their lives, like most young people, they are quite focused on their own interests and activities, and struggle to see the needs of the family as a whole. Now that their Grandpa needs more support from Anne, they may have to take more responsibility at home. While Anne knows her children are aware of the support Anne has given her parents over recent years, she does not expect them to support her in the same way, saying she would not want to burden them with such a responsibility.

At this time, the family story is continuing and the future undefined. Any plans remain quite tentative. Anne foresees considerable uncertainty related directly to her father’s condition. The experience she is having, of being the generation in-between frail older parents and growing children, is familiar to many people in her age group. A family ethic of caring ensures that Anne will continue the commitment to her father’s needs, and maybe by example, will influence her children’s attitudes to supporting ageing relatives in the future.
Family Stories

Anne’s Family Tree

Maternal Grandmother
Lived at home supported by a daughter (Anne’s aunt) who lived nearby
Died in her 80’s

Maternal Grandfather
Lived at home with his wife.
Died suddenly of a Myocardial Infarct or a Stroke when in his 70’s

Paternal Grandfather
Died when Anne’s father was an infant.
There was also a stepfather and a step sister but the family estrangement precluded contact

Paternal Grandmother
Her situation is unknown due to an estrangement from the family

Mother.
Lived at home with her husband, moving into an independent unit in a Retirement Village.
She died at 82 of Pulmonary Disease

Father.
Still alive and lives alone in an independent unit in a Retirement Village. He has early dementia.
He is 84 years old

Brother
Supports wife with her mother
Executor for Father
No practical assistance

Brother
Lives nearby
Provides occasional meals, financial assistance and EPA

Anne
Lives nearby and is close to Father
Assists with meals, laundry, shopping & social activities

Sister
Lives nearby and is close to Father
Assists with shopping, hospital appointments and occasional meals

Sister
Unmarried, more freedom
Lives further away
Not practical but provides more social interaction and company to Father

Son aged 24
Student at University

Daughter aged 21,
Working, Close relationship with Grandfather

Son aged 19
Recently made redundant
Little interaction with Grandfather
6.4 Pam’s family story

Many stories of multi-generational families living together describe stress and discord but Pam’s recollections of her mother living with her were happy. She talked warmly about what her mother meant to the extended family, commenting that it was not in her life plan to have her mother move in with her but she had never regretted the decision to share her home over a lengthy period of eleven years. Pam’s father had been unwell with a heart condition for about 12 years but despite these health concerns her parents continued to live in the family home with its large garden. Her father was a very keen gardener but increasingly needed help to maintain the grounds. However, her father became weaker over time and died at home from a sudden heart attack, leaving her mother alone.

Having worked in a Rest Home and being unhappy with the standard of services delivered, Pam vowed to prevent her mother from moving into a rest home. With her nursing experience Pam saw herself as the most likely one among her siblings to take on the caring role. Supporting her mother was just a continuation of the attention she had provided both parents prior to her father’s death as her three siblings live out of Auckland city. While she conceded that rest homes can be a comfortable place for older people, she wanted more for her mother and this included being encompassed within the family setting. Pam’s husband had a good relationship with his mother-in-law and encouraged the idea of her mother coming to live with them. Living in a small cottage in the grounds of the family home resolved issues of her mother’s loneliness and insecurity with the ensuing years highlighting the positive benefits of multi-generational households. Pam was also able to provide the 24 hour care needed when her mother became unwell and subsequently died of heart failure at the age of 91.

Having a parent live with her was not totally unusual for Pam as she and her siblings had experienced their paternal grandfather living with the family when they were young children. He was cared for by their mother and died at home when Pam was very young. She can also remember visiting her maternal grandparents as a teenager with her parents providing the practical assistance of mowing lawns and tending the garden. Both of Pam’s grandmothers lived in their own homes until they were well into their eighties with each dying in hospital. Her maternal grandfather lived at home until his death when he was in his mid-seventies.
For “Nana”, the move to living beside Pam and her family became a new phase in her life with the opportunity to be more involved in family events. Pam described her mother as being invigorated by this change in her living situation as she was able to maintain her independence with the added security offered by the closeness of family. Nana delighted in the younger generations of the family and developed a close bond with her great grandchildren. Pam reported that the children had no sense of Nana being old or ageing as she was simply part of the family and social setting. The older woman thrived on being included in the social circle surrounding Pam, her family, friends and neighbours.

Prior to her mother’s last illness the grandchildren had offered to “step in” and keep an eye on Nana, enabling Pam and her husband to travel. Although they rarely took up these offers Pam did come to depend on her children a little more as her mother became frailer; especially the eldest daughter who lived next door. It was only in the last three months of her life that deteriorating health lead to Pam’s mother to shift from her cottage into the house. At this time Nana suddenly lost all independence and came to rely increasingly on Pam and her husband to meet her basic needs. Pam adjusted her routine so that her mother was never alone, relying on her husband and children for extra assistance, most often to keep Nana company. Nana died at Pam’s house being attended to by her loving extended family.

**Pam’s reflections on future ageing**

Pam never considered her mother a burden as she was generally well and independent. The supportive role Pam adopted was never planned but simply happened in a gradual way, “evolving from one stage to the next”. She considered such a response to her parents ageing needs was reciprocating the caring she received as a child and as a result of their close relationship.

While Pam has impressed on her children that she does not expect them to care for her when she gets older she acknowledges that the care and attention she directed toward her parents may influence her children’s attitude towards supporting her should she need it in the future. Although not as actively involved in supporting their Nana as Pam and her husband, the grandchildren voiced their commitment to family by visiting the family home frequently and suggesting they support Nana to allow their parents to have a holiday.

From a financial perspective Pam reported that she and her husband have planned for their future older years, but where they would like to live is uncertain. They recognise the need to be near healthcare services and hospitals and Pam is clear that she does not wish her
children to feel obligated or burdened by ageing parents or to care for her in the same way she cared for Nana. However, if any of her children volunteered to support her as her needs changed she might accept their offer. What she would like is to live nearby her children in order to feel more secure and know help would be at hand if needed, perhaps in a similar set up to that of her mother. Pam believes her mother’s approach to this multi-generational living was a model she could apply to a similar setting; maintaining independence and courtesy toward family members while accepting their support as needed.
Family Stories

Pam’s Family Tree

Maternal Grandmother
Died aged 80. Lived in own home but died in hospital.

Maternal Grandfather
Died aged 74 years

Paternal Grandmother.
Separated from husband and lived with daughter. Died in hospital aged in her 80s

Paternal Grandfather.
Lived with son and family. Died at home aged in his 80s.

Mother.
Died aged 91 years. Lived in a cottage beside Pam’s home but moved in with her in last 3 months of life when she became unwell.

Father.
Died 82 years of a heart condition after 12 years of illness. Supported at home by his wife with house & garden maintenance & regular visits from family.

Sister.

Sister.
Lives north of Auckland. Irregular visits to mother. Very little support offered

Brother.
Lives north of Auckland. Reluctant visitor

Pam.
Offered practical support to both parents then had mother live on her property until her death.

Daughter.
Lives beside parents. Provided some support & company to Grandmother

Son.
Lives nearby and regularly visited Grandmother

Daughter.
Lives nearby and regularly visited Grandmother.
6.5 Suzanne’s family story

Knowledge of the facts of historical events fails to convey the human experience and the impact on the lives of those involved and their families. For Suzanne the first and second World Wars have had a lasting impact on her parents’ lives and she believes this history is an important part of her family.

Suzanne’s paternal grandfather joined the Army during World War I and was killed on the French front, leaving his wife with a six month old son. Suzanne recalls her grandmother, ‘Nana’, as a very stern Victorian lady, not always approving or warm. She never remarried, raising her son alone. Although Suzanne was about 10 years old when her Nana died, she has clear memories of visiting her; of shared Christmases and Sunday afternoon drives together. During the last two years of her life Nana moved into a flat attached to Suzanne’s parents’ house and her father was very attentive to her grandmother’s needs. She was aware that Nana did not approve of her daughter-in-law as she was ‘foreign’ and her housekeeping ways were different.

Prior to the outbreak of World War II, Suzanne’s maternal grandparents, who lived in Europe, were concerned for the safety of their daughter and arranged for her to move to England where she lived with a foster family. She was 14 years old when she left in 1939 and as far as the family can ascertain, her parents died in 1942, victims of the holocaust. Her mother does have some relatives in the United States, but essentially she was orphaned by the war.

Both Suzanne’s parents suffered the tragedy of losing parents when very young and of having no siblings to share their childhood with. She believed this mutual sense of loss may have been a factor that drew them together. Over the more than 50 years of marriage, her father has always been the calming influence in their relationship but her mother’s anxious tendencies have increased with her father’s onset of dementia. At the age of 91 her father is still physically able although he now uses a stick when walking. There are times when the ‘old spark’ is evident but his capacity to engage in conversation appears to be gradually fading.

For the past eight years Suzanne’s parents have lived independently in a cottage in a retirement village and receive regular assistance from a carer to give Suzanne’s mother a break from the continual vigilance required to ensure her father’s safety. Her father
continues to engage in tasks around their home, such as gardening and preparing meals. Suzanne sees her role as providing emotional support to her mother and to some extent taking her father’s previous role in decision-making by allowing her mother to talk about her ideas in the process of finding a resolution. She telephones her mother every night and discusses day-to-day management issues. Suzanne also provided relief for her mother by taking her father out in the car, to concerts, or for drives, and also either sleeping at her parent’s home or having her father stay at her home for an afternoon nap whenever possible. She has noticed the relentless need for her mother to be aware of what her father is doing and the disturbed night-time sleep is causing her mother to become very tired. Her mother has some difficulty in coping with her father’s occasional irritability associated with the dementia but generally finds strategies to manage. Suzanne reported her mother leans on her Christian beliefs, trying to be compassionate and look for the good aspects of the situation.

Suzanne does have the support of her brothers in caring for their parents. Her oldest brother lives in London with his wife and twin daughters. These little girls are the only children of the next generation and frequent visits and phone calls ensure they are developing a relationship with their Grandma and Grandpa. On a recent holiday, Suzanne observed the girls’ keenness to assist their Grandpa to walk to the car; walking at his pace and demonstrating an awareness of his frailty. Photographs record his enjoyment in reading to his grand-daughters. The girls’ father has set up and funds a system which allows their grandparents to readily access transport whenever needed. Suzanne’s other brother lives nearby and will often have their parents at his home for dinner. She regards him as the “strategic thinker” as he tends to be more decisive when decisions need to be made.

For Suzanne and her brothers the story of supporting and caring for their parents is unfinished. One of their concerns is organising the care their father needs, co-ordinating the various support agencies and carers and ensuring their 84 year old mother continues to cope. Suzanne is pragmatic about the future, acknowledging the uncertainty of how her parents individual needs will develop, but is committed to supporting them.

Suzanne’s reflections on future ageing
For Suzanne, the prospect of ageing and possibility of needing support with daily living is far in the future. She is considering her potential needs and is making tentative plans. She has an optimistic attitude to life and is confident of being as physically and mentally capable as
her mother is in her eighties. While the public perception of ageing tends to be negative, Suzanne was sure there are many older people leading active, involved lives.

Due to her family history Suzanne’s kinship network is small and she does not anticipate nor expect her nieces to support her as she ages, especially as there is no certainty they will be living in New Zealand when Suzanne is older. Currently single, Suzanne has not disregarded a future relationship but is confident of the support of both her brothers and believes their backing of each other is intrinsic to their family bonds. Suzanne has also built a network of friends she knows she can rely on, including several friends’ children who call her Aunty. She is unsure, however, whether these relationships will equate to the family support she and her brothers are presently giving their parents. Among her friends, establishing individual strengths and weaknesses is a way of helping each other, and Suzanne is convinced this assistance will continue into the future.

Caring for her parents has caused Suzanne to reflect on her own future. Presently, her home is easily managed, close to amenities and she expects it will meet her needs for the next 20 years. Past experience of flatting has lead Suzanne to reflect on a future which may include shared-housing. She cites the example of the Abbeyfield Trust which provides independent living for older people, similar to flatting, which appeals to Suzanne. She prefers the Abbeyfield model of residence to that of a retirement village where her parents live as they have experienced both management changes and variable service provision. Suzanne contemplates that the power of the Baby Boomer generation may forge a new way of managing aged care. She also believes that pensions and government support should still be available to care for people in the New Zealand society and looks forward to how such services will be handled.
Suzanne’s Family Tree

Maternal Grandfather
Died in 1942 in a German concentration camp.

Maternal Grandmother
Died in 1942 in a German concentration camp.

Paternal Grandmother
Died aged 89 years. Lived with sister until she died then with son & his family for last 2 years of her life

Paternal Grandfather
Died on the battlefield during the World War I

Mother
Aged 84 years old. Lives with husband. Is independent but has assistance with housework & support person to help with husband. Also relies on daughter for emotional support

Father
Aged 91 years. Lives with wife. Has dementia but physically reasonably well. Receives support from family and support person.

Brother
Lives overseas with his wife and daughters. Assists with financial support and practical when in NZ

Brother
Lives in Auckland. Provides practical support for parents, cooks meals & is available when needed.

Suzanne
Provides practical support, assists mother with decisions & companionship for father. Does not have children.

Twin daughters aged 7 years old. Live overseas with parents
Conclusion

The five family stories reveal some of the challenges and pleasures in caring for older relatives. At the time of compiling these stories both Suzanne and Anne were continuing to provide the functional care, and emotional and companionship support required by their surviving parents, two of whom were suffering from a form of dementia. Each of these stories reveal different issues for the adult child in helping their ageing and frail parents.

For Clare there was the challenges presented by the suddenness of her mother’s brain injury, sadness at the physical and personality changes wrought by this event and how the family came together to support her parents until their respective deaths. Jenny, whose previous experiencing of an ageing parent was limited to her mother’s residence in a rest home, discovered the depth of feelings associated with caring for her father as he was dying. She considered her own family had gained positively from the part each played in supporting their father-in-law and grandfather and the experience had become a vital piece of their family narrative. The experience continues for Anne and Suzanne as the effects of dementia on their fathers will require more support from family members and other services as their needs increase. Both have good relationships with their siblings and maintain regular communication to manage the current problems and plan for potential needs in the future.

Pam delighted in sharing her story of a mother, grandmother and great-grandmother who enjoyed being part of her extended family and sharing events over many years. She recalled with pleasure how her mother thrived on the relationships she developed with her grandchildren and great grandchildren and how caring for her mother was made easy by the older woman’s acceptance of the support around her.

The family trees provided a visual picture of how each generation is interlinked; how support between age groups developed through the modelling process and the contribution by made by the youngest family members to the care of their grandparents. Comments made by some of the participants indicated they had no expectations of their children for assistance with their future ageing needs as there was uncertainty about where this younger generation would be living and the commitments they may have when the interviewees were older. Others suggested they hoped that their modelling of caring behaviour toward their ageing parents would translate into a similar response from their children. Pam liked the idea of living in close proximity to her adult children and Anne expressed the view that the family ethic of care may influence her children in the future. Suzanne, the only participant without children, had a different approach to planning her older years which included not relying on
younger relatives but instead looking to friends and groups within society to provide the support she anticipated needing.

The variations in experiences of caring for older parents and the thoughts that these experiences had generated illustrate the wide range of possible problems and solutions for the future ageing population and how their ageing care needs might be managed. While the family stories provide insight into how each of the participants lived, and continue to live, with a commitment to supporting their parents, they also highlight similar findings from the focus groups and the survey detailed in the following chapters.
Chapter 7

Survey Findings

Well as far as I’m concerned at 75 I hope my health is good, giving me independence to live where I’m living now, with my children around me helping me, giving me support on a daily basis. (R113)

Introduction

The following chapter presents the results of the anonymous survey questionnaire. The descriptive statistics provided frequencies and percentages in relation to the forced answer questions and most of these are depicted in tables alongside identification of some features of the results. The findings are presented in three distinct parts: respondent characteristics, experiences of caring for an older person, and planning for ageing years. Questions were formulated from key issues that arose in focus groups meetings and individual interviews. Several questions allowed for respondents to make additional comments. Excerpts and summaries of these remarks are included in these results.

7.1 Respondent Characteristics

Demographic details of the postal survey respondents (see Appendix 15) included gender, age, ethnicity, make-up of respondents household, employment, home ownership, current state of health and fitness, and whether their parents (as recipients of age-related care) were alive. Of the 127 valid responses to the anonymous questionnaire 44 were men (34.64%) and 83 were women (65.36%). There were an additional 10 questionnaires received in which data was not included in the study as the respondents did not meet the age criteria (Table 7.1). The desired response rate of 300 questionnaires returned was not with 21 percent valid responses, a factor which impacts on the generalisability of the survey to the wider population.
Survey Findings

Table 7.1
Gender and Age Distribution of Respondents by Number and Percentage

<table>
<thead>
<tr>
<th>Age</th>
<th>Female</th>
<th>Male</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>40-44</td>
<td>12</td>
<td>6</td>
<td>18 (14.2)</td>
</tr>
<tr>
<td>45-49</td>
<td>12</td>
<td>4</td>
<td>16 (12.6)</td>
</tr>
<tr>
<td>50-54</td>
<td>20</td>
<td>9</td>
<td>29 (22.8)</td>
</tr>
<tr>
<td>55-59</td>
<td>16</td>
<td>12</td>
<td>28 (22.0)</td>
</tr>
<tr>
<td>60-64</td>
<td>23</td>
<td>13</td>
<td>36 (28.3)</td>
</tr>
<tr>
<td>Total</td>
<td>83 (65.36)</td>
<td>44 (34.64)</td>
<td>127 (100)</td>
</tr>
</tbody>
</table>

Numbers in brackets are percentages

Respondents named the ethnic group with which they most closely identified, with New Zealanders of European descent being the mostly frequently chosen option (n=106, 83.5%). The other ethnicities selected were Māori (5), Asian (5), Pacific Island (4) and Indian (2), and four identified as either Croatian, English, or South African (Table 7.2).

Table 7.2
Number and Percentage of Respondents by Gender and Ethnicity

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Female</th>
<th>Male</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>NZ European</td>
<td>68</td>
<td>38</td>
<td>106 (83.5)</td>
</tr>
<tr>
<td>Māori</td>
<td>4</td>
<td>1</td>
<td>5 (3.9)</td>
</tr>
<tr>
<td>Pacific Island</td>
<td>3</td>
<td>1</td>
<td>4 (3.1)</td>
</tr>
<tr>
<td>Asian</td>
<td>3</td>
<td>2</td>
<td>5 (3.9)</td>
</tr>
<tr>
<td>Indian</td>
<td>1</td>
<td>1</td>
<td>2 (1.6)</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>2</td>
<td>4 (3.1)</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>0</td>
<td>1 (0.8)</td>
</tr>
<tr>
<td>Totals</td>
<td>82</td>
<td>45</td>
<td>127 (100)</td>
</tr>
</tbody>
</table>

NZ = New Zealanders of European descent Numbers in brackets are percentages

Of the 127 responses, 116 (91.3%) indicated they lived in a house they owned either freehold with a mortgage or in a family trust and the remaining 11 (8.7%) rented from state or privately owned housing. Full-time paid employment was high amongst the respondents (n=76, 59.8%), with part-time paid employment being the second highest option (n=20, 15.7%). However five respondents indicated they were also caring for children and four caring for older people in addition to part-time or full-time work. Four of these were unable to seek paid work due to their caring responsibilities. Comments additional to forced answers
Survey Findings

included one respondent receiving a benefit and being involved in volunteer work and not seeking employment, and another reported he was not in paid employment as he and his wife cared for his father-in-law (Table 7.3).

Table 7.3
Respondents Employment Status and Additional Caring Role

<table>
<thead>
<tr>
<th>Employment</th>
<th>N</th>
<th>Caring Role:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Older person</td>
</tr>
<tr>
<td>Full-time</td>
<td>76 (59.8)</td>
<td>1</td>
</tr>
<tr>
<td>Part-time</td>
<td>20 (15.7)</td>
<td>1</td>
</tr>
<tr>
<td>Homemaker</td>
<td>6 (4.7)</td>
<td>0</td>
</tr>
<tr>
<td>Self-employed</td>
<td>16 (12.7)</td>
<td>1</td>
</tr>
<tr>
<td>Unemployed</td>
<td>1 (0.8)</td>
<td>0</td>
</tr>
<tr>
<td>Beneficiary, Retired or Student</td>
<td>8 (6.3)</td>
<td>2</td>
</tr>
<tr>
<td>Totals</td>
<td>127 (100)</td>
<td>5</td>
</tr>
</tbody>
</table>

Numbers in brackets are percentages

Most households comprised of the respondent living with their spouse or partner (n=90, 70.9%), with the second largest category living alone (n=16, 12.6%) and 21 (16.5%) reported living with children, grandchildren, parents, grandparents, friends or flatmates. In addition to a spouse, partner or other relative 50 (39.4%) people reported sharing their home with children and/or grandchildren, 3 (2.4%) with parents or grandparents, and 2 (1.6%) with a friend or flatmate. One respondent reported her parents rotated their living location equally between her and three siblings. However, as she already had four school age children, this meant the family comprised of eight people from three generations living together for three months each year (Table 6.4).
### Survey Findings

**Table 7.4**  
*Respondents' Household Characteristics*

<table>
<thead>
<tr>
<th>Household</th>
<th>N</th>
<th>Other occupants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse or Partner</td>
<td>90 (70.9)</td>
<td>0</td>
</tr>
<tr>
<td>Children/Grandchildren</td>
<td>13 (10.2)</td>
<td>50 (39.4)</td>
</tr>
<tr>
<td>Parents/Grandparents</td>
<td>3 (2.4)</td>
<td>3 (2.4)</td>
</tr>
<tr>
<td>Friend/Flatmate</td>
<td>5 (3.9)</td>
<td>2 (1.6)</td>
</tr>
<tr>
<td>Live Alone</td>
<td>16 (12.6)</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>127 (100)</td>
<td>55 (43.4)</td>
</tr>
</tbody>
</table>

Numbers in brackets are percentages

Sixty-three (49.6%) of respondents indicated they shared their home with children (possibly adult) or grandchildren, and in some cases both with some including other adults as well. The age of the children were categorised into four groups; 0-5 years, 6-12 years, 13-17 years and 18 years and over with respondents having the option of selecting from none to four or more children in each category. A large percentage indicated they did not have children living with them but 23 of those living in a multi-generational home had one child, the rest having two or more with the age ranging from preschool through to over 18 years (Table 7.5).

**Table 7.5**  
*Number and Ages of Children Living with Respondents*

<table>
<thead>
<tr>
<th>Ages</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4+</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-5 years</td>
<td>118 (92.9)</td>
<td>8 (6.3)</td>
<td>1 (0.8)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>6-12 years</td>
<td>110 (86.6)</td>
<td>9 (7.1)</td>
<td>7 (5.5)</td>
<td>0</td>
<td>1 (0.8)</td>
</tr>
<tr>
<td>13-17 years</td>
<td>102 (80.3)</td>
<td>18 (14.2)</td>
<td>6 (4.7)</td>
<td>1 (0.8)</td>
<td>0</td>
</tr>
<tr>
<td>18+ years</td>
<td>89 (70.1)</td>
<td>26 (20.5)</td>
<td>10 (7.9)</td>
<td>1 (0.8)</td>
<td>1 (0.8)</td>
</tr>
</tbody>
</table>

Numbers in brackets are percentages

Using a five-point Likert scale from very poor to excellent respondents determined their current state of health and level of fitness. The majority of respondents considered their health was very good or excellent (n= 93, 73.2%), average (n=33, 26%), with one (0.8%) choosing poor. However, the percentage selecting the very good to excellent option for their
current level of fitness diminished to 47 (39%) with the majority of 63 (49.6%) opting for average and 17 (20.6%) choosing poor or very poor (Table 7.6).

Table 7.6
Respondents Self-rated Health and Fitness

<table>
<thead>
<tr>
<th>Very Poor</th>
<th>Poor</th>
<th>Average</th>
<th>Very good</th>
<th>Excellent</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Current</td>
<td>0</td>
<td>1 (0.8)</td>
<td>33 (26.0)</td>
<td>64 (50.4)</td>
<td>29 (22.8)</td>
</tr>
<tr>
<td>health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current</td>
<td>1 (0.8)</td>
<td>16 (12.6)</td>
<td>63 (49.6)</td>
<td>36 (28.3)</td>
<td>11 (8.7)</td>
</tr>
<tr>
<td>fitness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Numbers in brackets are percentages

As parents are the most frequent recipient of age-related support needs from the mid-life adults, respondents were asked to indicate whether their parents were still alive and if so to rate their current state of health and level of independence. Seventy six (59.8%) of the respondents reported their mother was alive and 56 (44.9%) rated her health as average, very good or excellent, with 18 (14.2%) rated as poor or very poor. Not all the respondents who indicated their mother was still alive rated her level of independence but those who did 57 (46.7%) indicated levels of average to excellent and 13 (10.6%) were poor to very poor.

Forty six (36.2%) respondents indicated their father was alive with 34 (26.7%) of the fathers reported as having average to excellent state of health and 12 (9.4%) having poor health. Three respondents did not rate their father’s level of independence but seven (5.6%) indicated their father had poor or very poor independence, with the rest (n=36, 29.1%) selecting average to excellent independence.

7.2 Experience of caring for an older person

The second section of the survey sought answers regarding the experiences of caring for an older person, including the support offered, perceptions of the impact of providing such assistance, involvement by other family members and access to formal services.

Almost half of the respondents (n=62, 48.8%) indicated they were currently or had in the past cared for an older person with 53 (41.7%) caring for a parent, six (4.7%) a mother or father-in-law, and three (2.4%) nominating a grandparent, aunt or uncle, or family friend. The
Survey Findings

age at which time approximately half of these respondents began providing assistance was 75-84 years (n=33, 26%) with 14 (11.0%) indicating 65-74 years and 15 (11.8%) indicating 85 years or older.

Respondents were asked to nominate the type and frequency of assistance provided. The most frequently offered support was companionship followed closely by driving the older person to appointments and assisting with shopping. The least recurrence of assistance was for bathing and dressing although only 19 of the 127 respondents indicated the older person received government funded assistance for this activity (Table 7.7).

Respondents were able to make additional comments regarding assistance offered. Twenty people made a range of statements grouped into associated supports offered to the older person. Functional services included assisting with bathing and dressing when the support worker was unavailable, doing laundry, transporting to visit other family members and advocating for additional services. Healthcare services were arranged through the respondent setting up and attending doctors’ appointments, redressing wounds and supervising medication administration. Legal and financial matters were addressed with respondents negotiating with lawyers and real estate agents. Emotional support was also identified with one respondent reporting making daily telephone calls to the older person.

Table 7.7
Type of Assistance and Frequency of Provision by Respondents to the Older Person

<table>
<thead>
<tr>
<th>Task</th>
<th>Occasionally</th>
<th>Up 4x monthly</th>
<th>Daily</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bathing/dressing</td>
<td>13 (10)</td>
<td>4 (3)</td>
<td>7 (6)</td>
<td>24 (19)</td>
</tr>
<tr>
<td>Meal preparation</td>
<td>11 (9)</td>
<td>16 (12)</td>
<td>19 (15)</td>
<td>46 (36)</td>
</tr>
<tr>
<td>Shopping</td>
<td>10 (8)</td>
<td>34 (27)</td>
<td>8 (6)</td>
<td>52 (41)</td>
</tr>
<tr>
<td>Companionship</td>
<td>4 (3)</td>
<td>25 (20)</td>
<td>27 (21)</td>
<td>56 (44)</td>
</tr>
<tr>
<td>Housework</td>
<td>13 (10)</td>
<td>15 (12)</td>
<td>12 (9)</td>
<td>40 (31)</td>
</tr>
<tr>
<td>House maintenance</td>
<td>13 (10)</td>
<td>16 (13)</td>
<td>4 (3)</td>
<td>33 (26)</td>
</tr>
<tr>
<td>Gardening</td>
<td>23 (18)</td>
<td>9 (7)</td>
<td>9 (7)</td>
<td>41 (32)</td>
</tr>
<tr>
<td>Driving to appointments</td>
<td>17 (13)</td>
<td>26 (21)</td>
<td>10 (8)</td>
<td>53 (42)</td>
</tr>
<tr>
<td>Finances</td>
<td>15 (11)</td>
<td>14 (11)</td>
<td>11 (9)</td>
<td>40 (31)</td>
</tr>
</tbody>
</table>

Numbers in brackets are percentages
Survey Findings

The motivation for providing assistance or supporting the older person was challenged in a series of forced answer questions requiring the respondent to make a choice from strongly disagree to strongly agree. Not all of the respondents (n=62, 48.8%) who indicated they had offered support to the older person answered these questions (Table 7.8).

Table 7.8
Respondents’ Rating of Motivation for Supporting the Older Person

<table>
<thead>
<tr>
<th>Motivation</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Love for older person</td>
<td>0</td>
<td>4 (6.6)</td>
<td>6 (9.8)</td>
<td>9 (14.8)</td>
<td>42 (68.9)</td>
<td>61 (100)</td>
</tr>
<tr>
<td>Sense of duty</td>
<td>7 (11.7)</td>
<td>4 (6.7)</td>
<td>8 (13.3)</td>
<td>15 (25.0)</td>
<td>26 (43.3)</td>
<td>60 (100)</td>
</tr>
<tr>
<td>Guilt</td>
<td>33 (56.9)</td>
<td>9 (15.5)</td>
<td>9 (15.5)</td>
<td>4 (6.9)</td>
<td>3 (5.2)</td>
<td>58 (100)</td>
</tr>
<tr>
<td>Family expectations</td>
<td>22 (38.6)</td>
<td>9 (15.8)</td>
<td>12 (21.1)</td>
<td>9 (15.8)</td>
<td>5 (8.8)</td>
<td>57 (100)</td>
</tr>
<tr>
<td>Society expectations</td>
<td>29 (50.0)</td>
<td>8 (13.8)</td>
<td>11 (19.0)</td>
<td>7 (12.1)</td>
<td>3 (5.2)</td>
<td>58 (100)</td>
</tr>
<tr>
<td>No-one else available</td>
<td>16 (27.1)</td>
<td>4 (6.8)</td>
<td>17 (28.8)</td>
<td>13 (22.0)</td>
<td>9 (15.3)</td>
<td>59 (100)</td>
</tr>
<tr>
<td>Older person's expectations</td>
<td>17 (29.3)</td>
<td>6 (10.3)</td>
<td>14 (24.1)</td>
<td>12 (20.7)</td>
<td>9 (15.5)</td>
<td>58 (100)</td>
</tr>
</tbody>
</table>

Numbers in brackets are percentages

However all respondents who indicated they had offered support to the older person (n=62, 48.8%) responded to the questions on the impact of providing this support. Again using the forced-answer Likert scale, respondents were asked to rate the pleasure they derived from giving support, resentment about the impact on time in their daily life, and impact on the time spent with their own family. While most agreed or strongly agreed about the satisfaction gained from offering support (n=54, 87.1%), concern was expressed by 28 (45.2%) choosing agree or strongly agree options regarding the impact of providing support on time available for their own family (Table 7.9).
Table 7.9
Respondents’ Rating of the Experience of Providing Support to the Older Person

<table>
<thead>
<tr>
<th></th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact of Support</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Derived pleasure</td>
<td>0</td>
<td>3 (4.8)</td>
<td>5 (8.1)</td>
<td>25 (40.3)</td>
<td>29 (46.8)</td>
<td>62 (100)</td>
</tr>
<tr>
<td>Resented time on daily life</td>
<td>23 (37.1)</td>
<td>15 (24.2)</td>
<td>17 (27.4)</td>
<td>5 (8.1)</td>
<td>2 (3.2)</td>
<td>62 (100)</td>
</tr>
<tr>
<td>Impacted on time with own family</td>
<td>11 (17.7)</td>
<td>11 (17.7)</td>
<td>12 (19.4)</td>
<td>20 (32.3)</td>
<td>8 (12.9)</td>
<td>62 (100)</td>
</tr>
</tbody>
</table>

Numbers in brackets are percentages

Of the 62 respondents who indicated they supported an older person, 41 (66.1%) reported other family members also provided assistance, although this support was variable. While most respondents selected agreement or strong agreement for the reason distantly located relatives offered limited support (n=34, 54.8%), other reasons receiving a similar level of agreement included family time constraints (n=17, 31.5%), and employment constraints (n=16, 26.2%), unwillingness (n=12, 22.2%) or disinterest in providing assistance (n=11, 20.4%), with financial constraints (n=8, 14.9%) receiving the least agreement. Comments from respondents identified many additional reasons why other family member did not assist with the older person’s needs. These explanations included denial about the help required, differing abilities and time to assist, providing assistance only when it suited them, intermittent support from siblings living overseas, general disinterest or living nearby but being useless (R101). One respondent reported her sister-in-law resisted the need for her husband to assist his parents, and another commented her working husband was an only child with time constraints meaning she was left to care for her parents-in-law. Siblings’ physical and emotional health also provided limitations as a clash of personalities between family members and the older person. On a positive note one respondent described giving assistance as: it is our culture to help our parents. We love being with them. They provide guidance and direction to all of us (R78).

Respondents were asked to consider the pressure that may have been exerted on them to offer support to the older person. Using a five point Likert scale from strongly disagree to strongly agree respondents rated the pressure exerted on them by family members, health professionals, the older person, and religious or cultural groups. The high percentages
selecting disagreement or strong disagreement for religious or cultural groups (n=50, 89.2%), friends (n= 46, 78%), health professional (n= 41, 70.6%) and family (n=34, 59.7%) indicated respondents did not feel undue pressure to support the older person. However, when asked if the older person had exerted pressure to provide support 29 respondents (50.9%) agreed or strongly agreed they had not been subjected to such coercion but 19 (33.3%) indicated the older person had influenced their decision to provide support with 9 (15.8%) remaining neutral. A few respondents commented on difficulties for the older person including financial problems leading to poor quality of life and living circumstances, and a view that rest homes provided a poor standard of care. One respondent remarked that she loved her mother-in-law and never questioned the need to support (R25).

Few respondents answered the question asking if the older person received government funded support, however mobility, visual and hearing aids (n=26, 86.7%), housework (n=24, 80%), and bathing and dressing assistance (n=19, 86.4%) were the most frequently reported. Additional comments indicated the older person also received supports such as subsidised residential care, medical costs and public transport, and a St John’s alarm.

In answer to the question on why the older person did not receive government funded support there was, again, a limited response. Twenty four (55.8%) reported the older person was ineligible based on an income assessment, 24 (55.8%) expected the family to provide support, and 21 (51.2%) were unaware government support was available. Several of the respondents expanded on the reasons for the older person being ineligible for government funded support such as already receiving a benefit, owning a home of greater value than the asset threshold, or in one case the mother having dementia resulting in not being aware of available support services. Another respondent reported she was expected to support her mother after she had dismissed the assistance received for shopping, bathing and dressing.

7.3 Planning for ageing years

The last section of the survey questionnaire focused on the respondents’ planning for their own ageing needs. Questions included financial planning for retirement, determining responsibility for a variety of daily living activities they may need support with as they age, and expectations on family for support or functional assistance.

Sixty two respondents (48.8%) acknowledged previously having cared for an older person, the experience of which may have influenced their responses to the questions on future age-
Survey Findings

related support provisions. Of the 127 responses, 90 (70.9%) indicated they contributed to a superannuation fund and 35 (27.6%) did not belong to a savings scheme, and two (1.5%) did not answer the question. A further 93 (73.2%) confirmed they were making provisions for their retirement, 26 (20.5%) had not made any provisions and eight (6.2%) did not answer the question.

Respondents were asked to determine between themselves, their family or government as to who should be responsible for providing a selection of services or supports to meet their age-related needs. The results indicated a strong sense of personal responsibility for provisions related to housework (n=96, 75.6%), gardening (n=91, 71.7%) house maintenance (n=84, 66.1%), bathing/dressing (n=76, 59.8%) and shopping assistance (n=63, 49.6%). To a lesser extent respondents accepted liability for transport to medical appointments (n=55, 43.3%), paying for medical care (n=55, 43.3%), paying for full-time community-based care (n=42, 33.1%), full-time residential care (n=41, 32.2%), and mobility aids and rails (n=40, 31.5%). However, it is also apparent that respondents expected the government to be accountable for their ageing needs, in particular, full-time community care (n=72, 56.7%), full-time residential care (n=70, 55.1%), mobility aids and rails (n=68, 53.5%) and the cost of medical care (n=63, 49.6%). More reliance on family was indicated for assistance with shopping (n=39, 30.7%), transport to medical appointments (n=35, 27.6%), and to a less extent, house maintenance (n=25, 19.7%) (Table 7.10).
Table 7.10
Respondents' Choice of Responsibility for Age-related Care Provision

<table>
<thead>
<tr>
<th>Responsibility</th>
<th>Respondent</th>
<th>Respondent's family</th>
<th>Government</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Services/supports</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Housework</td>
<td>96 (75.6)</td>
<td>8 (6.3)</td>
<td>16 (12.6)</td>
<td>120 (100)</td>
</tr>
<tr>
<td>House maintenance</td>
<td>84 (66.1)</td>
<td>25 (19.7)</td>
<td>10 (7.9)</td>
<td>119 (100)</td>
</tr>
<tr>
<td>Gardening</td>
<td>91 (71.1)</td>
<td>18 (14.2)</td>
<td>9 (7.1)</td>
<td>118 (100)</td>
</tr>
<tr>
<td>Bathing/dressing</td>
<td>76 (59.8)</td>
<td>14 (11.0)</td>
<td>29 (22.8)</td>
<td>119 (100)</td>
</tr>
<tr>
<td>Mobility aids/rails</td>
<td>40 (31.5)</td>
<td>11 (8.7)</td>
<td>68 (53.5)</td>
<td>119 (100)</td>
</tr>
<tr>
<td>Transport to medical appointments</td>
<td>55 (43.3)</td>
<td>35 (27.6)</td>
<td>32 (25.3)</td>
<td>122 (100)</td>
</tr>
<tr>
<td>Shopping assistance</td>
<td>63 (49.6)</td>
<td>39 (30.7)</td>
<td>16 (12.6)</td>
<td>118 (100)</td>
</tr>
<tr>
<td>Paying for medical care</td>
<td>55 (43.3)</td>
<td>4 (3.1)</td>
<td>63 (49.6)</td>
<td>122 (100)</td>
</tr>
<tr>
<td>Paying for full-time residential care</td>
<td>41 (32.2)</td>
<td>6 (4.7)</td>
<td>70 (55.1)</td>
<td>117 (100)</td>
</tr>
<tr>
<td>Paying for full-time community care</td>
<td>42 (33.1)</td>
<td>5 (3.9)</td>
<td>72 (56.7)</td>
<td>119 (100)</td>
</tr>
</tbody>
</table>

Numbers in brackets are percentages

Comments from the respondents indicated they felt the state had some responsibility for supporting the age-related needs of older people. One respondent claimed that while he had made provision for retirement he had also ‘paid tax at the highest rate for 30 years [and] expect the government to look after me in my retirement as per the social responsibility of the government’ (R101). These sentiments were supported by another respondent who proposed ‘the government should pay a weekly allowance to old people sufficiently so they don’t need to worry about basic needs’ (R120). Other respondents suggested the responsibility for supporting older people should be shared amongst the individual, their family, government agencies and a range of community organisations, such as the Salvation Army and other church groups, and the Returned Services Association. Some respondents acknowledged that the government may not be able to fund older people’s support needs while others emphasised that the family should not be expected to provide all the support.
When asked to consider factors that would influence their choice of age-related support of most importance to the respondents was the desire to maintain their independence (n=125, 98.4%). It was clear respondents did not wish to be a burden to their family (n=111, 88.1%), and many assumed the younger members of their family would already have commitments to employment and children, meaning limited time for the ageing parents (n=98, 78.4%). Only 11% (n=14) considered their relationship with family members was not good enough to expected support, with 7.9% (n=10) having no contact at all with their relatives (Table 7.11).

**Table 7.11**

*Factors Influencing Respondents’ Choice of Age-related Supports*

<table>
<thead>
<tr>
<th>Factors influencing choice of age-related supports</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do not want to burden family</td>
<td>111 (87.4)</td>
<td>12 (9.4)</td>
<td>123 (100)</td>
</tr>
<tr>
<td>Family have work/child commitments</td>
<td>98 (77.2)</td>
<td>20 (15.7)</td>
<td>118 (100)</td>
</tr>
<tr>
<td>Retain my independence</td>
<td>125 (98.4)</td>
<td>2 (1.6)</td>
<td>127 (100)</td>
</tr>
<tr>
<td>Family located elsewhere</td>
<td>47 (37.0)</td>
<td>64 (50.4)</td>
<td>111 (100)</td>
</tr>
<tr>
<td>Family cannot afford support</td>
<td>63 (49.6)</td>
<td>50 (39.4)</td>
<td>113 (100)</td>
</tr>
<tr>
<td>Poor relationship, no contact with family</td>
<td>14 (11.0)</td>
<td>99 (78.0)</td>
<td>113 (100)</td>
</tr>
<tr>
<td>No family to offer support</td>
<td>29 (22.8)</td>
<td>87 (68.5)</td>
<td>116 (100)</td>
</tr>
</tbody>
</table>

Numbers in brackets are percentages

Many respondents made additional comments on the factors influencing their choice of support for their future ageing. Some stated they wanted to be well prepared and financially independent as they grew older and to live close to family. However, several respondents indicated their children or other possible supportive family members lived overseas or their future location was uncertain at this time, and others reported having no children or family who could offer support. Another respondent suggested the next generation would need to be a two-income family which would make it ‘a lot more difficult for them to support ageing parents, both financially and time-wise’ (R11). Many respondents indicated they came from a supportive family but also commented on not wanting to be a burden to their children as their own parents had been to them. One commented on an interest in ‘alternative mixed living housing which apply life-cycle ageing in place design and support – where you can live with family and friends in a peer support environment’ (R127).

Respondents were asked to indicate the factors they considered most important when determining their choice of location and type of residence as they grew older. Using a five
point Likert scale of forced choices ranging from least important to most important, a low maintenance property was the important or most important influencing factor for 104 (82.4%) of all the respondents. Also in the same categories of importance respondents chose proximity to public transport (n=91, 71.7%), proximity to shops (n=89, 70.6%), living closer to family (n=82, 64.6%), proximity to healthcare services (n=80, 63.0%), a smaller home than their current house (n=79, 62.2%), and living in a warmer climate (n=66, 52.4%). The least or of no importance was placed on living in a retirement village (n=71, 56.3%) (Table 7.12).

Table 7.12
Respondents’ Options for Living Locality in Their Older Years

<table>
<thead>
<tr>
<th>Option</th>
<th>Least important N (%)</th>
<th>Not important N (%)</th>
<th>Neutral N (%)</th>
<th>Important N (%)</th>
<th>Most important N (%)</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Near family</td>
<td>9 (7.4)</td>
<td>5 (4.1)</td>
<td>25 (20.7)</td>
<td>33 (27.3)</td>
<td>49 (40.5)</td>
<td>121 (100)</td>
</tr>
<tr>
<td>Low maintenance home</td>
<td>1 (0.8)</td>
<td>4 (3.1)</td>
<td>17 (13.4)</td>
<td>26 (20.5)</td>
<td>78 (61.9)</td>
<td>126 (100)</td>
</tr>
<tr>
<td>Small home</td>
<td>17 (13.5)</td>
<td>11 (8.7)</td>
<td>19 (15.1)</td>
<td>34 (27.0)</td>
<td>45 (35.7)</td>
<td>126 (100)</td>
</tr>
<tr>
<td>Near healthcare services</td>
<td>7 (5.6)</td>
<td>11 (8.7)</td>
<td>28 (22.2)</td>
<td>35 (27.8)</td>
<td>45 (35.7)</td>
<td>126 (100)</td>
</tr>
<tr>
<td>Near shops</td>
<td>2 (1.6)</td>
<td>6 (4.8)</td>
<td>29 (23.0)</td>
<td>45 (35.7)</td>
<td>44 (34.9)</td>
<td>126 (100)</td>
</tr>
<tr>
<td>Near public transport</td>
<td>4 (3.2)</td>
<td>7 (5.6)</td>
<td>24 (19.0)</td>
<td>42 (33.3)</td>
<td>49 (38.9)</td>
<td>126 (100)</td>
</tr>
<tr>
<td>A warmer climate</td>
<td>14 (11.1)</td>
<td>9 (7.1)</td>
<td>37 (29.4)</td>
<td>29 (23.0)</td>
<td>37 (29.4)</td>
<td>126 (100)</td>
</tr>
<tr>
<td>Retirement Village</td>
<td>44 (34.9)</td>
<td>27 (21.4)</td>
<td>30 (23.8)</td>
<td>13 (10.3)</td>
<td>12 (9.5)</td>
<td>126 (100)</td>
</tr>
</tbody>
</table>

Numbers in brackets are percentages

On a five point Likert scale respondents were asked to indicate their reasons for choosing to move closer to family. The options offered were to assist with grandchildren, receive companionship or to receive assistance from family members. Companionship was indicated in the agree/strongly agree categories by 71 (57.7%) followed closely by assisting with grandchildren (n=60, 49.6%). However, respondents were evenly divided on the reason for moving closer to family being to receiving their assistance with 41 (34.7%) disagreeing or strongly disagreeing, 44 (35.5%) being neutral and 37 (29.8%) agreeing or strongly
agrees. Comments from respondents emphasised the wish not to be a burden to their family, but also a desire to have a reciprocal relationship. They want to maintain their independence and have easy access to services, but also enjoy companionship from their adult children. One stated that moving closer to family would only occur after a ‘discussion about what that would mean for us and them. A move would only be undertaken with serious consideration’ (R50).

Similarly, when asked to determine the likelihood of accepting assistance from family members to meet their potential age-related needs, the responses recorded were fairly evenly distributed across the five forced options from very likely to very unlikely. However, of particular note was the recording of very unlikely/unlikely of 95 (76.0%) in response to family paying for full-time residential care, 94 (75.2%) payment for medical care, 77 (61.1%) for assistance with bathing and dressing and 58 (46.8%) that family would pay for mobility aids. Despite these figures it was still evident that the respondents would accept some support assistance from family across all options to meet their potential ageing needs (Table 7.13).

<table>
<thead>
<tr>
<th>Family support</th>
<th>Very unlikely</th>
<th>Unlikely</th>
<th>Neutral</th>
<th>Likely</th>
<th>Very likely</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housework</td>
<td>23 (18.5)</td>
<td>26 (21.0)</td>
<td>35 (28.2)</td>
<td>24 (19.4)</td>
<td>16 (12.9)</td>
<td>124 (100)</td>
</tr>
<tr>
<td>House maintenance</td>
<td>13 (10.5)</td>
<td>17 (13.7)</td>
<td>36 (53.2)</td>
<td>37 (29.8)</td>
<td>21 (16.9)</td>
<td>124 (100)</td>
</tr>
<tr>
<td>Gardening</td>
<td>18 (14.5)</td>
<td>23 (18.5)</td>
<td>35 (28.2)</td>
<td>35 (28.2)</td>
<td>13 (10.5)</td>
<td>124 (100)</td>
</tr>
<tr>
<td>Bathing and dressing</td>
<td>41 (32.5)</td>
<td>36 (28.6)</td>
<td>27 (21.4)</td>
<td>11 (8.7)</td>
<td>11 (8.7)</td>
<td>126 (100)</td>
</tr>
<tr>
<td>Pay for mobility aids</td>
<td>58 (46.8)</td>
<td>27 (21.8)</td>
<td>20 (16.1)</td>
<td>11 (8.7)</td>
<td>8 (6.5)</td>
<td>124 (100)</td>
</tr>
<tr>
<td>Transport to appointments</td>
<td>18 (14.4)</td>
<td>20 (16.0)</td>
<td>45 (36.0)</td>
<td>25 (20.0)</td>
<td>17 (13.6)</td>
<td>125 (100)</td>
</tr>
<tr>
<td>Shopping assistance</td>
<td>16 (13.0)</td>
<td>20 (16.3)</td>
<td>39 (31.7)</td>
<td>33 (26.8)</td>
<td>15 (12.2)</td>
<td>123 (100)</td>
</tr>
<tr>
<td>Pay for medical care</td>
<td>63 (50.4)</td>
<td>31 (24.8)</td>
<td>18 (14.4)</td>
<td>4 (3.2)</td>
<td>9 (7.2)</td>
<td>125 (100)</td>
</tr>
<tr>
<td>Pay for full-time residential care</td>
<td>75 (60.0)</td>
<td>20 (16.0)</td>
<td>19 (15.2)</td>
<td>3 (2.4)</td>
<td>8 (6.4)</td>
<td>125 (100)</td>
</tr>
</tbody>
</table>

Numbers in brackets are percentages

When asked to nominate the person most likely to assist them with personal, household and financial needs as they grew older the popular option was the respondent’s daughter,
Survey Findings

followed by their son. However, 47 (37.9%) recorded having no-one/other to assist with their financial needs, 22 (17.5%), with their household needs, and 15 (11.9%) with their personal needs. Comments from the respondents indicated a strong tendency to expect the government to provide the necessary support as they had no family or did not wish family to be involved in their age-related care needs (Table 7.14).

Table 7.14
Respondents' Choice of Person Most Likely to Support Their Ageing Needs

<table>
<thead>
<tr>
<th>Personal needs</th>
<th>Household needs</th>
<th>Financial needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most likely assistant</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Daughter</td>
<td>66 (52.4)</td>
<td>57 (45.2)</td>
</tr>
<tr>
<td>Son</td>
<td>22 (17.5)</td>
<td>24 (19.0)</td>
</tr>
<tr>
<td>Grandchild</td>
<td>0</td>
<td>1 (0.8)</td>
</tr>
<tr>
<td>Niece or Nephew</td>
<td>7 (5.6)</td>
<td>6 (4.8)</td>
</tr>
<tr>
<td>Neighbour or friend</td>
<td>3 (2.4)</td>
<td>4 (3.2)</td>
</tr>
<tr>
<td>Partner</td>
<td>13 (10.3)</td>
<td>12 (9.5)</td>
</tr>
<tr>
<td>No-one/other</td>
<td>15 (11.9)</td>
<td>22 (17.5)</td>
</tr>
<tr>
<td>Total</td>
<td>126 (100)</td>
<td>126 (100)</td>
</tr>
</tbody>
</table>

Numbers in brackets are percentages

The final question required the respondent to imagine their future at 75 years of age and comment on where they would be living and how their support needs would be met. Three respondents did not answer the question but the other 124 provided a wide range of options. Some responses were quite specific about the location where they planned to live; commonly near the sea. Many expected to still be living in their current property providing they had a reasonable state of health and fitness, while others indicated they wanted to live in a smaller, low maintenance, possibly single-level property. Several respondents included a wish to be close to family but retain their independence, although quite a few indicated they would like family support too. Respondents commented on the wish to be financially independent or be able to rely on their own resources to fund support services they may need to continue living independently in the community. They indicated however, that their financial resources would largely be from superannuation and the government retirement pension. A few stated they still wanted to be in part-time paid employment, and three wrote that they had ‘no idea’ (R44, 60, 125). The substance of the responses is best summed up by the following quote: ‘well as far as I'm concerned at 75 I hope my health is good, giving
me independence to live where I’m living now, with my children around me helping me, giving me support on a daily basis’ (R113).

Conclusion

This chapter summarises findings from the survey. Details of the results are presented in distinct sections which relate to the format of the questionnaire and provide respondent characteristics, views on their experiences of caring for an older person, and indications of planning for their own age-related care needs and living arrangements. The majority of respondents were of European ethnicity and two-thirds in full or part-time employment. While 77 percent of respondents considered they were in good health, only 36 percent considered their level of fitness was good or better.

Evaluation of the survey findings and those from the focus groups and interviews are presented in the discussion chapter which considers the results of this study in relation to the literature and New Zealand government policies and funding related to aged-care services.
Chapter 8

Discussion:

Many more people are living longer and it is necessary to develop views on what arrangements will need to be made to help ensure their health is maintained and they have a good quality of life. (Dalziel, 2008, p. 1)

Introduction

The mid-life adult or Baby Boomer cohort has had momentous impact on many social facets of life in Western countries (Biggs, et al., 2007) and it can be presumed they will continue reshaping their ideas and attitudes as they grow older. Figures on population growth indicate a decrease in the number of children in the population, which extrapolated to the future working-age group, suggest fewer people to engage in support services roles and fewer tax payers to meet the costs of healthcare and home-based support services for a growing older population. Government concerns about funding for retirees are valid, especially given the healthy life expectancy years of the population (Ministry of Health, 2011a). The Baby Boomer cohort has the potential to impact significantly on New Zealand’s resources of appropriate housing, healthcare services, home-based and residential care. While the number of older people is expected to gradually diminish by mid-21st century as the bulk of the Baby Boomers die, in the interim, when the need for aged-care support is at its peak, there will be a colossal demand on both services and personnel to address the needs of older people.

Contrary to claims that ageing Baby Boomer cohort is more likely to maintain a healthy lifestyle and independence in retirement, Australian figures on obesity, cardiovascular disease and diabetes predict worsening health outcomes (Biggs, et al., 2007; Quine & Carter, 2006). These debilitating diseases are also prevalent in the New Zealand population (Ministry of Health, 2011a). Therefore, it cannot be assumed that future older people will be healthier than their forebears. Predictions do point to a growing number of people exceeding 85 years by the year 2050 (Booth, et al., 2007), and it is well known that the prevalence of chronic illness and disability increases with advanced age (Barrett, 2006; Hansen-Kyle, 2005; Hartman-Stein & Potkanowicz, 2003; Strawbridge, et al., 2002; van Maanen, 2006). The consequence of ageing, illness and disability will be the need for support services to meet the older person’s functional capacity and preserve their ability to live independently.
The logical conclusion is that, in order to uphold New Zealand government policies on ageing the aged-care services must be provided by public funding, augmented where possible by social networks and family members of the older person.

The aim of this study was to garner information on the experience of caring for an older person and how this affected the life and family of the participants. The aim was also to discover whether these experiences had influenced the participants’ thoughts regarding their future ageing and how they anticipated their ageing needs might be addressed. Both of these aims were met. Previous studies have identified many issues of ageing, such as safety risks for older people living alone, availability of family support, and caregiver burden. Family support is significant in enabling the older person to preserve their independence; a factor confirmed by participants through their descriptions of caring for an older person. Not previously established is whether the experience of caring for an older person provided insights on the ageing process and influenced caregivers’ perceptions of their future old age. The main purpose of the study was to ascertain whether these experiences had influenced participants’ attitudes to ageing, and in particular their attendance to health and well-being, planning for future housing and financial needs, and expectations of how their ageing support needs might be met. Failure to acknowledge and prepare for the ageing process will have consequences for the older person and their family as well as the healthcare system responsible for providing disability support services.

Findings from the focus groups, interviews and survey have been integrated with the term ‘participants’ used throughout the discussion. The discussion focuses on two areas: (i) participants’ insights on ageing derived from their experiences of caring for an older person and how this has shaped their views on ageing, and (ii) participants’ expectations and planning in preparation for their own ageing years. While some of this study’s findings confirm published research, especially regarding caregiver burden, conflicting demands and family caring, the issue of preparedness for future ageing, access to appropriate support services for disabled older people, and expectations on younger generations has not previously been reported.
8.1 The experience of caring for an older person

Life course perspective theory clearly establishes an association between intergenerational influences and the ties that maintain family cohesion and relationships. It is recognised that connections between family members ensure continuity of relationships, regardless of social change and life challenges (Bengston, et al., 2002). Previous studies confirm the importance of family bonds in the act of nurturing and caring across the generations (Ingersoll-Dayton, et al., 2001; Piercy, 2007; Willson, et al., 2003). These relationship bonds and family values were very evident in participants’ descriptions of caring for an older person; ideals that contributed to participants’ motivation and willingness to assist the older person when ill-health or disability reduced their functional capacity.

A strong motivator for participants to assist the older person was reciprocating the care they acknowledged receiving during their formative years. The act of reciprocity relates to intergenerational relationships and the commitment of family members to support one another. Driven by emotional attachment and shaped by the individual relationship and past experiences, reciprocity eases the pressures people experience as they transition through life (Cooney, 2000; de Jong Gierveld & Havens, 2004; Ingersoll-Dayton, et al., 2001; Piercy, 2007; Tinker, 2002). Regardless of the strength of reciprocity between family members, participants expressed a sense of responsibility toward the older person; providing support even when doing so proved challenging. While participants revealed a great many concerns from their experiences of caring for an older person, the following discussion centres on the demands of the caregiver role and the consequential need for formal support services.

Caregiver stress

While much has been written about caregiver stress it was important to explore the participant’s’ experience as caregivers of older people to provide the context from which their reflections on ageing were generated. Participants confirmed many of the findings of previous studies which identified the main elements of caregiver stress related to conflicting commitments, emotional demands from the older person, and lack of support from other family members (Grundy & Henretta, 2006; Hareven, 2000; Ingersoll-Dayton, et al., 2001; Sebern, 2005; Spillman & Pezzin; 2000). They also revealed many experiences that contradicted previous studies or were not apparent in the literature; findings that contribute to the body of knowledge on the challenges of caring for an older person.
Participants cited examples of the older person having a health crisis, increasing disability or diminishing capacity to attend to their daily needs as the point where they initiated practical support. The literature confirms the advent of an accident or acute illness as commonly precipitating the development of the caregiver role of an older relative (Bromley & Blieszner, 1997; Davey, 2006). Associated with the development of illness and disability is the need for choices to be made regarding healthcare options. One of the many concerns expressed by participants was the sense of becoming a ‘parent’ to their parents and having to make decisions about the older person’s medical care and living arrangements. While participants accepted their role in supporting the older person they experienced difficulty in being the principal decision-maker when the older people delegated such responsibility to them. The reasons for the older person opting out of making decisions about their care needs was not known but it should be noted that this finding conflicted with literature that highlighted older people’s desire to preserve their independence of choice in living arrangements, care and support (Randers & Mattiasson, 2004). Along with the onus of responsibility, the insidious development of the older person’s needs required a lot of time and emotional energy from participants; demands that adversely impacted on other areas of their lives. Nearly half of these mid-life adults reported that caring for the older person impacted on the time available for their own families. While the majority of participants reported deriving pleasure from caring for the older person, a few openly expressed their feelings of frustration and resentment in relation to the loss of personal plans and dreams, set aside in deference to their duty to the older person. The available literature does not explain the effects on the caregiver of delaying life plans in deference to the needs of an older person, making these factors appropriate to explore in more depth in future research.

Stress and the burden of responsibility were factors participants linked directly to the competing demands on their time, fear of neglecting other responsibilities, and their emotional commitment to the older person. These findings concur with the literature that identified the difficulties associated with the many roles and obligations alongside supporting an older person (Arksey & Glendinning, 2007; Grundy & Henretta, 2006; Hareven, 2000; Sebern, 2005; Spillman & Pezzin, 2000; Wolf & Soldo, 2009). Most of the participants were women who identified as a daughter of the older person they supported; a finding confirmed in previous studies that cited daughters as the most likely person to care for older parents, regardless of their family and employment commitments (Grundy & Henretta, 2006; Spillman & Pezzin, 2000; Wall & Spira, 2006). What is most interesting is that, despite the multiple roles and responsibilities many women cope with and having experienced caregiving stress, the majority of participants indicated a preference for a daughter to be their caregiver as they
aged. Whether the choice of a daughter as caregiver is associated with an expectation of reciprocity for the parenting role, relationship familiarity or a disinclination to have a stranger provide assistance is at this time unknown but would be of interest for future research.

The multitude of responsibilities for children, partners and to employers proved to be a significant constraint for participants in providing the level of support the older person needed. In reporting the imbalance in functional support from other family members participants also conceded that geographical location and family responsibilities placed limitations on siblings providing meaningful assistance to the older person. Such inequities in the assistance from other family members has been recognised as causing additional stress and frustration to the main caregiver (Ingersoll-Dayton, et al., 2003; Roff, et al., 2007). However, the issue of proximity to the older person may be more prevalent in New Zealand with the tendency for internal migration within country (Keeling, 2001; Statistics New Zealand, 2002). Along with the more recent economic situation leading many young adults to leave New Zealand in search of employment opportunities these migratory factors will undoubtedly have an impact on the traditional family and intergenerational support structures that rely on living in close proximity leading to greater reliance on support services.

Māori participants’ perspectives
It is well recognised that the Māori people have experienced significant repercussions from the European colonisation of New Zealand, especially with respect to inequalities in health, morbidity and mortality figures, and socioeconomic well-being (Harris, et al., 2006). Māori participants spoke with sadness about the loss of the whānau support structures that traditionally had ensured their older people were cared for as they aged. Concern was also expressed about the lack of respect shown toward older people in the whānau by many young Māori. Participants attributed this self-centred attitude to the influence of Western culture, and inferred that these young Māori family members could not be relied upon to care for their ageing relatives. However, some of the participants cited examples of multi-generational caring and a willingness of younger Māori whānau members to support their older relatives. Although participants reported variable contributions by extended family to the older person support needs, and difficulties accessing appropriate government-funded disability support services, there was an appreciation of the services provided by Māori community centres. In fact the most positive experiences of caring for an older person were those related by a few of the Māori participants who indicated a great appreciation for their elders.


Discussion

**Disability support services**

Availability of formal support services to older people living in the community is acknowledged as being a major contributor to maintaining their independence (Cheek, et al., 2006; Jörgensen, 2007; Themessl-Huber, et al., 2007; Vladek, 2005). One of the key findings of this study was the difficulty participants’ experienced in accessing timely and appropriate support services for the older person with physical and/or cognitive disabilities. In fact, involvement in a focus group proved enlightening for some participants as they listened to the experiences of other group members and learnt more about available services. Even those with some familiarity with the health sector expressed frustration at the difficulties they experienced in trying to ensure appropriate services were secured to enable the older person to continue living independently. These findings infer there is a lack of meaningful information for both the older person and their caregivers on how to access support services that correspond to the older person’s needs.

Participants’ accounts also revealed considerable differences in the provision of government-funded support services depending on where the older person lived, with a greater range of supports available in large urban areas compared to smaller regional centres. Even within a large city like Auckland participants identified differences in support services between the DHBs. While support services for those with physical disabilities were satisfactory, participants were critical of the appropriateness of supports provided, especially for the particular needs of older people with dementia. Differences were also revealed between ACC and DSS in relation to ease of access and level of support provided. While the origin of a person’s disability may be either through an accident or chronic illness, the resulting functional changes could be similar. However, services provided by ACC were more extensive and generous compared to DSS. Even attempts by some participants to self-fund care-worker support for the older person were met with failure; a factor they attributed to the scarcity of suitable people willing to provide such a service. Very little is known about the availability of care-workers to support the older person living in the community. However, North (2011) identified shortages in qualified nurses to work with the growing number of older people with chronic conditions; a finding which has implications for the policies that promote independence in the older population and the health sector workforce.

What this study has exposed is challenges to the provision of support services for older people with disabilities. Thus measures need to be taken to address the ease of access to the information on eligibility to support services and the suitability of services provided. The diversity in services offered to those meeting entitlement suggests an inconsistency in either
the assessment processes or distribution of support services, and quite possibly the funding arrangements that underpin the resources to meet individual needs. These findings have implications for older people striving to preserve their independence, especially if they have limited family support.

Very few of the total number of participants reported that the older person received formal functional assistance in the home, however the support services identified were limited to mobility, visual and hearing aids, housework and assistance with bathing and dressing. It was evident that participants were frequently assisting the older person, especially with meal preparation, shopping and transport to appointments. The majority of participants also provided companionship, many on a daily basis, to the older person. Given the difficulty in accessing appropriate support services it is inevitable that the needs of the older person will have to be met by available family members; increasing the caregiver’s physical and emotional stress. Participants recognised that a direct consequence of the limited access or availability of formal support services and the challenges in meeting the older person’s practical needs increased the likelihood of admission to residential care; an outcome observed by other researchers (Cheek, et al., 2006, Jörgensen, 2007). Many participants expressed concern about the standards of care in residential care facilities and expressed the view that residential care did not provide a good quality of life. Findings from this study have revealed two major issues for participants who cared for an older person; firstly, information about the older person’s entitlement and ease of access to disability support services, and secondly, the appropriateness of the services provided created considerable frustration for both the caregiver and the older person.

8.2 Expectations and plans for future ageing

Extensive literature to date has clearly articulated the manner in which the mid-life adult or Baby Boomer generation has forged a path through life. The Baby Boomers life trajectory is predicted to be very different from their parents or grandparents, with more emphasis on leisure, lifestyle and consumerism, and changing attitudes toward education and career pathways, marriage, divorce and childbearing (Arber, et al., 2003b; Biggs, et al., 2007; Fairhurst, 2003; Longino, 2005; Pink, 2004; Quine & Carter, 2006). Comments from participants reflect some of the literature with expressed intentions to continue in part-time paid work as a transition into retirement, the need to maintain physical and mental well-being, and having living arrangements that would accommodate their ageing needs.
However, what this study has also uncovered is that, while participants have gained insights into ageing from their experiences of caring for an older person, their ideas of managing their future ageing requirements were vague and unformed. The sense of denial about the ageing process was quite evident in their comments; perhaps an understandable position from mid-life adults in relation to their present stage on the life trajectory. Yet to refute the inevitability of ageing also precludes the planning and preparation that would support an individual’s choice of how their older years are lived. However, the majority of participants did acknowledge personal responsibility for functional supports, such as personal care, housework and maintenance. Nevertheless, there was a clear indication that a greater number of these mid-life adults expected government funding for their potential mobility aids, medical costs, and community or residential care.

The economic constraints resulting from the global financial situation can be expected to impact on health sector spending for the foreseeable future. For many of the future older people the likelihood of limited assistance from scarce government-funded support services forecasts a gloomy outlook for maintaining their independence. The consequences of inadequate support services will force many older people with disabilities to increasingly depend on family members; relatives whose capacity to provide support may also be constrained due to other commitments or geographical distance. While the majority of participants clearly did not want to be a burden to their family as they aged, many contradicted these assertions by revealing the hope that their children would contribute to their future support needs. Four important aspects of the findings are discussed in greater depth; health and independence, financial considerations, housing options, and family support. Participants revealed attitudes and expectations at variance from previous research or commentary; differences that have implications for the ageing population and government of New Zealand.

Health and independence

When asked to self-rate their health and fitness, the majority of participants indicated their current health status was very good, but fitness levels were average. One notable social change for the Baby Boomer generation has been a trend toward increasing physical activity as a means of improving or maintaining a sense of well-being, perhaps in an effort to stave off the negative effects of age-related chronic illness and disability (Hartman-Stein & Potkanowicz, 2003). The population cohort has also demonstrated keenness toward leisure activities with an emphasis on a healthier lifestyle (Longino, 2005). Participants argued that their cohort had taken a more active approach to health and well-being and were mindful of
Discussion

not becoming a future liability to their children or government-funded services. They expressed an awareness of the benefits of exercise and healthy eating, confirming previous studies that claimed the maintenance of physical strength improved a person’s sense of self satisfaction, well-being and resilience to age-related changes (Alex, 2010; Nygren, et al., 2005; Quine & Carter, 2006; Peri, et al., 2007; Wall & Spira, 2006).

While there was limited discussion of participation in physical exercise most of these mid-life adults were already coping with the multiple roles and expectations presented by family commitments and paid employment. Time constraints imposed by such competing demands has been known to place limitations on engagement in personal interests such as physical exercise or leisure activities (Grundy & Henretta, 2006; Wall & Spira, 2006). Although the Baby Boomers are predicted to experience less long-term chronic illnesses, through a combination of medical advances and healthier lifestyles (Longino, 2005), any impediment to involvement in regular exercise infers negative consequences for the health and well-being of these individuals as they age.

Older people are renowned for their resilience and ability to cope with the challenges of life (Antonucci, et al., 2002; Hansen-Kyle, 2005; Kahn & Juster, 2002). Unfortunately, depression is a well-recognised and negative effect of ageing, disability and illness, and a factor in lowering the resilience to adversity (Mehta, et al., 2008). The issue of mental health was discussed in relation to participants’ observations of cognitive decline or depression in the older person they supported. While participants’ stressed the importance of keeping the mind active by pursuing intellectual interests, the discussion centred on generalities and no specific methods on how this would be achieved were identified. It remains to be seen how these mid-life adults adapt to their inevitable ageing and maintain their physical and mental health, independence and a lifestyle they aspire to.

The anticipated longevity for the current mid-life adult implies the probability of a lengthier period of time between retirement and death (Dunstan, 2006). Participants varied in their expectations of when they would commence retirement from paid employment with some expressing the intention of working for as long as possible while others relished the prospect of gaining more time to pursue personal interests. Whichever path these people take, management of personal finances will be essential to preserving life-style choices into the future.
Discussion

Financial considerations

Financial planning is a very complex issue, no more so than at a time of economic uncertainty. It has been reported that the on-going global financial crisis will have adversely affected the assets accrued by some mid-life adults in preparation for their future retirement (Gaynor, 2007). The consequences of such asset losses will leave many people facing impending retirement solely reliant on government-funded superannuation to meet their financial needs; a factor that has implications for the New Zealand government (Wilson & Rodway, 2006). The link between financial status and an individual's well-being in old age has already been well-established (Falkingham & Grundy, 2006; Gunnarsson, 2002; Hansen-Kyle, 2005). Therefore, it was interesting that participants were reluctant to acknowledge their future older years and revealed many contradictions and uncertainties regarding the financial planning which would provide some choice of lifestyle as they aged.

While hesitant to discuss future ageing, several participants reported their plan to continue working in paid employment well into their older years. Although not addressed in this study, it is possible that continuing in paid employment was not simply participants' reluctance to concede to ageing but the need to accrue assets for a standard of living that could not be funded solely by the government pension. A few participants did acknowledge the difficulty of financing their daily living expenses and supporting children with the cost of tertiary education meant they were struggling to accrue savings; the likely outcome being reliance on the government for financial support in retirement. Parenting responsibilities are known to impact on employment patterns, earning capacity, superannuation contributions and financial well-being for many women (Quine & Carter, 2006), all factors acknowledged by female participants as having a significant effect on provisioning for their future retirement.

Despite the hesitancy evident in discussing future ageing it was interesting to learn that many participants were making voluntary provisions for their retirement through a superannuation fund or some form of asset accumulation. Saving schemes such as superannuation are expected to provide a safeguard against the prospect of financial hardship in old age (Falkingham & Grundy, 2006). Regardless of their claims of saving for the future participants exhibited an expectation that the government would provide for their older years through community-based support services and medical care, and residential care. Many regarded such funded support would be a reciprocation for the years of paying government taxes; a belief strongly imbedded in the social welfare structure of New Zealand society. Ultimately, an individual's ability to accumulate assets, including home ownership
will determine how well they can self-fund their lifestyle choices and age-related needs in retirement beyond the limited support from the social welfare system.

**Housing options**

There has been some debate as to the protective effect of home ownership on potential poverty for older people, nevertheless, the rising cost of housing impacts on affordability; meaning some sectors of society will never be in a position to live in a house they have purchased (Wood, et al., 2011). The majority of participants reported living in a home they owned, a finding that differs from census figures indicating home ownership, across all ethnic groups, has decreased over the ten years from 73.8 percent in 1991 to 67.8 percent in 2001 (Statistics New Zealand, 2008). The New Zealand statistics are at variance to other OECD countries such as Australia, Canada, UK, USA, Ireland, France and Germany where home ownership has continued to rise over the same time period (Thorns, 2000). Some of the factors attributed to lower rates of home ownership included changes to family composition, such as relationship dissolution, and prioritising income into perceived high return investments rather than home ownership (Solomou, et al., 1998).

Participants showed insight into the importance of a low maintenance home and location close to services, such as shops, public transport and healthcare facilities, in enabling the older person to continue living independently. Several participants had identified safety risks for the older person; in particular the practical difficulties of effectively managing daily activities and the risk of falling. The older person’s reluctance to relocate to more suitable housing was a common and frustrating experience for several participants; a factor also noted by Askham, et al. (2000). Therefore it was interesting that many participants admitted a refusal to concede the possibility of age-related physical limitations. Despite an initial reluctance to discuss appropriate housing for their older years, participants’ reflections observations on the older person’s ease of access and mobility in the home lead some to change their ideas on housing options. Most participants acknowledged the importance of living in an easily maintained home in close proximity to healthcare services and public amenities. Other housing options identified by participants included a small flat adjacent to younger relatives, cohabitating with friends or a sibling, or communal living offered by organisations such as the Abbeyfield Trust, the Salvation Army, and the Veterans’ Association.

Discussion on the option of retirement villages revealed quite diverse opinions on the positive and negative attributes of such accommodation. Lack demographic variation and
limited social interaction with younger people, and evidence of many residents dying were viewed as undesirable aspects of village living by a few participants. In contrast, several participants considered the wide range of activities and social events organised within the village setting were a positive attribute which could counter the loneliness experienced by many older people.

From the wide variation in views expressed it was evident that limited consideration had been given by participants to the possibility of relocating to accommodation that catered for the changing practical needs of an older person. These findings reveal the lack of forward planning, especially for those nearing retirement, in terms of both preferred housing options and financial preparedness. Notwithstanding these divergent ideas, participants did identify the circumstances they considered would determine their ability to continue living independently; in particular their state of health, physical fitness, and proximity to family. Although a few participants reported having limited contact with relatives or no family at all, the vast majority placed high importance on living close to their relatives.

**Family support**

The life course perspective theory also makes a clear association between trajectories; the expectation of a life plan, and transitions; the changing roles as people age (Elder, 2007). The life plan for many participants included maintaining the family connections with young relatives in a similar manner to those relationships shared with the older generations. Participants identified a commitment to their relationship with the older person and the care they required while still maintaining, albeit with some difficulty, their own life trajectory of developing a career and supporting a young family. They also acknowledged the role transitions they experienced over many years; of becoming parents, then grandparents, and the prospect of future retirement. Despite expressions of a strong determination not to become a burden to their children, the majority of participants anticipated receiving some form of family assistance as they aged. They spoke of living nearer to their adult children and linked the concept of close family ties as being both a natural and desirable component of the daily life of older people. The desire to be near relatives may have been in recognition of the problems participants perceived with the older person they had cared for who lived alone in the community. Participants acknowledged the importance of social and family networks and expressed the wish to preserve these connections as they aged. Social networks and family relationships are known to be significant in maintaining the older person’s independence (Cheek, et al., 2006; Petrie, 2006; Tinker, 2002).
Caring for an older person had provided participants with insights into the ageing process and clearly influenced participants’ perceptions and attitudes to ageing. The challenges of physical and cognitive changes, loneliness, depression, safety issues associated with living alone, suitability of housing for people with disabilities, and the difficulty of accessing appropriate support services were cited by participants as the most significant issues for the older person. Yet, despite the advantage of these insights there was evidence of a dichotomy with participants’ reflections on the own future. Many participants demonstrated denial toward the notion of ageing and preparedness for transition into retirement and old age. Many participants affirmed the need to preserve their physical and mental well-being as they aged but few acknowledged involvement in activities to enhance physical health and fitness. While the majority claimed to have made some form of financial provision for retirement they still anticipated receiving support from the government-funded superannuation benefit. Even while reporting the inappropriate living arrangements of the older person in their care, few participants had considered relocating to a home more suitable to their potential ageing needs.

Regardless of a declared intention to avoid burdening their adult children, participants expressed the desire to be close to family whom they saw as the most likely people to provide support as they aged. They also conveyed a pervasive attitude of entitlement to government-funded aged-care support services, particularly medical care, mobility aids, community-based and residential care, and superannuation. Together these findings reiterate the challenges of the looming older population and their families, and have implications for the government ministries accountable for meeting policy objectives and delivering support services to older people.

8.4 Study strengths and limitations
The aim of this study was to explore mid-life adults’ experiences of caring for older people and how these experiences influenced their ideas and planning for their own future ageing. Of particular interest were the participants’ expectations of both family support and government support services to meet their needs as they aged. The findings provided a wealth of information on the topic, allowing a deeper understanding of the issues for future older people and the social, family and government supports they anticipate to meet their ageing needs.

Both focus groups and survey methods of collecting data have well recognised advantages and limitations. One of the advantages of focus groups is the ability to amass a considerable
Discussion

amount of information simultaneously from people who have experienced similar phenomena. Self-selection by participants infers a particular interest in the topic which can lead to the possibility of individuals manipulating the group dynamics. Managing the group process to allow for equity in sharing experiences and perspectives was managed by skilful direction from the facilitator through the use of question prompts, encouraging each participant to tell their story, and ensuring no person dominated the discussion.

Postal surveys are a widely used tool to gain specific data from a large number of people with the advantage of being a relatively quick and inexpensive process that affords the respondents the opportunity to offer honest answers without of any repercussions (Polit, et al., 2001). However, the low response rate for this study survey (n=127, 20%) was disappointing and restricted any ability to generalise to the wider population of mid-life adults in New Zealand. This response rate equates to a Type II error where the ability to ascertain a statistically significant result was negated by having too few responses (Watson, et al., 2008). There may have been several reasons for the low number of valid responses, including the recipient’s inability to read or write English or disinterest in the topic. While the intention of the survey was to make comparisons with findings from the focus groups and interviews data any meaningful statistical comparisons were precluded by the small number of responses. The use of the mixed methods approach allows for the phenomena of interest to be explored from different perspectives and, potentially, with a reasonably large number of participants thus increasing confidence in the accuracy of the findings (Adam & Kiger, 2002). Nevertheless, while these methods have provided an abundance of data on the phenomena of interest, caution must be taken in making generalisations to the wider population of New Zealand, especially given the low response rate to the postal survey.

Conclusion

As an exploratory study on a subject that is both topical and critical for the population of New Zealand the findings have illuminated many issues for the future older population, their families, and the government that warrant closer scrutiny. The realisation of the impending growth in the number of people aged 65 and older seems only now to have become part of the collective consciousness through exposure in the media. The central focus of the media discussion has been the cost of funding superannuation or the age-related pension for an increasing older population. However, what this study has highlighted is the deficits in planning and funding of community-based disability support services appropriate for the individual needs of older people, the provision of residential care facilities for the impending
Discussion

number of older people requiring such support, a sufficient nursing and support workforce knowledgeable in the needs of older people and implications for the families of the future older population. Such a lack of planning is a failure on the part of successive governments to acknowledge the impact the ageing population will have on all aspects of New Zealand society.

One important finding from the study was the difficulties participants and the older person experienced in accessing appropriate support services; services known to facilitate older people in maintaining their independence. These difficulties ranged from the lack of information on eligibility to support services to the ease of access or appropriateness of support services for the specific needs of the older person. Limitations in both availability and suitability of support services point to a significant concern for the maintenance of independent living for the older population. In spite of these experiences many participants expected the government to provide for any support services they may require in the future. Such a sense of entitlement can be linked to the social welfare structure of New Zealand society and confidence of reciprocation for taxes paid to the government.

The New Zealand government has increased funding for disability support services across all ages with the total expenditure being 7.4 percent of the health budget (Ministry of Health, 2011b). However, at less than 0.5 percent of GDP, this allocation is the second lowest among OECD member countries (OECD, 2005), figures that infer that the New Zealand government is less committed to the concept of ageing-in-place than the Health for Older People Strategy objectives demand. The limited funding may also be a reason why securing knowledge of entitlement and accessing disability support services had proven so difficult for many of the participants and the older person they supported.

Another key finding was the obvious vagueness regarding the many aspects of age-related needs and apparent expectations in this future older population, regardless of their experiences of caring for an older person. Many participants emphasised the importance of maintaining good physical and mental health, and independence as a means of limiting the effects of ageing, but a lack of practical application to such ideals infers the likelihood of developing similar chronic illnesses and disabilities as previous generations. Revelations of variable financial preparation for the future lead many participants to admit to inevitable reliance on the government-funded pension as the main source of income in retirement. The seeming lack of planning for the future is of concern.
Together, these discoveries point to significant consequences for the New Zealand government policies on ageing and provision of disability support services. New Zealand faces an impending crisis in meeting the needs of older people who are projected to number 25 percent of the population by 2050, a quarter of whom will be 85 years and older (Booth, et al., 2007). A proposal to alter the age of eligibility for superannuation may alleviate some of the concerns regarding anticipated government expenditure on superannuation but does not address the long-term planning necessary to develop adequate funds to facilitate this benefit as well as the healthcare and support services. An expectation of serious shortages in healthcare personnel, including registered nurses, support workers and specialist medical staff, has already been identified (North, 2011). In addition, there is a recognised need for improvement in education, remuneration and recognition for nurses and support workers who provide appropriate and on-going support of older people (Reed, et al., 2007; Reinhard & Young, 2009).

These findings also have significant implications for the families of the ageing population. Without adequate support services and the personnel to provide care, many older people will have no option but to rely on relatives for functional assistance to continue living in the community. The evident constraints on family caregivers will make such expectations of support unrealistic, leading to increasing demands on an already inadequate support service. The challenge for the current and future policy makers and government ministries in New Zealand is to attend to these significant issues before the surge of older people needing support services overwhelms the healthcare sector.

The concluding chapter outlines the implications and recommendations from this study and are directed at the New Zealand government policies on ageing, the planning and funding of disability support services, nursing and care workers education and remuneration, and public information in order to address the many issues facing this country in relation to the actual and potential need of the growing number of older people.
Chapter 9

Implications and Recommendations

Introduction

The life course perspective theory has provided the foundation structure for a study that sought to gain an understanding of how providing support for an older person influenced the mid-life adult caregiver’s expectations and planning for their own ageing years. Of particular interest were participants’ views on the challenges of ageing and their expectations of younger generations and government-funded services for future ageing needs. At the heart of the theory are the components of trajectory and transition, both of which have been applied to the study. Given their current trajectory it is likely these Baby Boomers will continue to forge a different path through life from that of their parents, with later transitions into parenthood and retirement from paid employment. Just how the Baby Boomer generation shape their ageing years can only be the subject of future research, however, the one undeniable trajectory for all people is that of growing older.

New Zealand’s Ageing-in-Place policy actively encourages an attitude among older people of retaining their independence as they age (Dyson, 2002). While existing knowledge recognises the increasing need for disability support services for older people living independently, the paucity of support services in New Zealand, among the lowest in the OECD (OECD, 2005), coupled with increasing longevity of a growing population of older people will inevitably make the practical support of such a policy unsustainable. It is inevitable that the situation will develop where increasing numbers of older people are forced to rely on less available government-funded supports due to limited family support and personal funds. The consequences of inadequate support of older people is an increasing likelihood of accidents in the home resulting in the need of acute hospital services or increased rates of admission to residential care. Both outcomes amount to an increase in demand on the healthcare budget already constrained by the expectations of the wider population. Additionally, the lower fertility rate of the population will result in a smaller workforce to both fund disability support services through taxes and provide the nursing and carer workforce to meet the needs of this burgeoning older population.

Disability or reduced functional capacity for the growing number of older people has emerged as a major sphere of concern for industrialised countries such as New Zealand
Implications and Recommendations

(Jacobzone, 2000). With the combination of greater life expectancy and decreased fertility rates there are likely to be fewer younger people to care for an increasingly ageing population (Barrett, 2006). Of even greater concern is the evident constraints to family support which paired with limited government-funded support services are liable to force many older people into residential care when their support needs cannot be adequately met in the community; both factors identified by participants in this study. Despite having variable knowledge of or experience with disability support services, it was certainly clear that participants had an expectation of receiving some form of subsidised support as required in the future.

The findings from this research, along with the knowledge of the paucity of government-funded support services, shortages of nursing and workforce personnel, and limitations to family assistance point to challenges in ensuring the future older population can ‘age in place’ successfully. It can confidently be assumed that future demands for support services for older people with disabilities will exceed supply unless substantial changes are made to funding structures and workforce development. Implications for government policies and funded services for older people are highlighted with particular emphasis on the potential for family support and the provision of support services from the nursing and carer workforce.

9.1 Family support for older people

The Australian government, with knowledge of the escalating number of older people has adjusted their policies in relation to ageing, placing greater emphasis on the family to take responsibility for the needs of their ageing relatives (Quine & Carter, 2006). From a pragmatic perspective, encouraging more personal accountability for addressing aged care needs, and involving the extended family, eases the financial burden on the government of supporting this population group. In New Zealand, means-testing is applied to determine the older person’s entitlement to a range of support services, and while some care is fully-funded through DHBs, DSS and ACC, there is the expectation that the older person will pay the full cost of residential care until their assets have diminished to NZ$200,000 (Ashton, 2000; Schofield, et al., 2006; Wilson, 2010). Many older people will not have the financial resources to self-fund their community-based or residential care, instead relying on funding from the government through its allocation to the DHBs. Such dependence on government funding may become unsustainable as the numbers of older people requiring residential care continues to grow.
Implications and Recommendations

A few participants acknowledged the scarcity of government-funded support services which would require them take more responsibility for their future age-related needs. The disparity between expectations of formal care and the funding allocated for such services provision infers greater reliance on family, friends or neighbours for older people requiring assistance. In New Zealand, older people may be financially better off than their counterparts in other OECD countries, but there is evidence of rising rates of poverty in the working age group with evidence of an increasing necessity for two income households to meet the cost of living (OECD, 2008). Such poverty ratings may stem from the high levels of personal debt incurred through the tertiary student loan scheme, which, while providing better employment prospects, also entails financial commitment to servicing the liability at a time when the young adult may be raising a family and striving for home ownership. A corollary of more working age adults in paid employment is less time available to care for older people.

While family may have been the most assured form of support in the past, it is unclear how much an older person can realistically rely on adult children for support in the future when dynamics such as employment commitments and proximity to family are considered. These mid-life adults are the most likely people to provide practical assistance to the older person but both internal and external migration precludes such support. Together, these commitments and constraints indicate family care of older people, even if encouraged by the government, may not be realistic, prompting a greater demand for formal support services.

9.2 Support services for older people

Regardless of the social networks and family support older people may receive the advent of chronic ill-health and disability will interfere with their ability to live independently. It is recognised that disability and loss of function is a looming problem for older people in industrialised countries with the inadequate functional support from family, friends or healthcare services being a catalyst for the older person’s admission to residential care (Cheek, et al, 2006; Jacobzone, 2000; Jörgensen, 2007). Day Care Centres have been known to contribute to a reduction in morbidity and mortality rates, and residential care admissions for older people (Andersson Svidén, et al., 2004; Elkan, et al., 2001; Kuzya, et al., 2006). However, the limited number of community-based day centres in New Zealand aim to provide a social outlet for older people, not support services that foster independence (Presbyterian Support, n. d.; The Selwyn Foundation, 2010).

Amongst OECD countries, the average expenditure on home-based support services for older people is 30.4 percentage as a share of the cost of long-term care, while New Zealand
Implications and Recommendations

expends a comparatively low 17.7 percentage (Booth, et al., 2007). As the age projections for this country are closely aligned with other OECD countries, such as Australia and the USA, these figures point to a deficit in future funded support services for an ageing population (Anderson & Hussey, 2000). The New Zealand Government's annual budget for 2012-2013 attempts to address the need for such resources by increasing the funding of disability supports for all age groups by $143.7 million over the following four years. Of this funding $54.7 would be directed to home and community support services and $57.6 million to residential care (English, 2012). While a commendable increase in funding, the allocation will need to increase significantly to address the disability support needs of the projected population of older people over the next four decades. One significant impediment to the allocation of government funding for a variety of services has been the impact of the severe earthquakes of 2010-2011 in Christchurch, New Zealand’s second largest city. The government has committed to a contribution of $5.5 billion over the next six years toward an estimated $25 billion rebuilding of the city (Canterbury Earthquake Recovery Authority, 2012). The financial consequences of the damaging earthquakes will inevitably be felt by other sectors reliant on government funding.

Objectives of government policies and strategies are to foster a healthier, fitter and more independent population, especially as they pass the age of 65 years. According to the MoH, the structure of service provision is uniform across the 20 DHBs aimed at equitable health and disability services provision (Ministry of Health, 2011c). Participants’ difficulties in accessing services highlighted the lack of clear communication between the assessors of need, service providers, recipients and their families. New Zealand residents are entitled to receive some funded assistance, relative to assessed need, to preserve their independence. There are a range of entitlements for people over 65 years, all requiring eligibility criteria be met (Ministry of Social Development, n. d.). Given the government’s tight control of benefit expenditure older people may increasingly need to turn to family for assistance, assuming there are relatives in a position to assist.

The number of people requiring services at home is high and makes demands on a workforce already struggling to cope (Booth, et al., 2007; Stone & Harahan, 2010). The process of supply and demand, evident in the aged-care sector workforce, and public funding of services leaves limited capacity to meet the increasing needs of older people (Eyers & Bryan, 2006). Additionally, as the older person’s disability or chronic illness worsens, their need for support increases, putting even more stress on an already struggling resource, particularly the nursing workforce (Byrne, Brady, Horan, Macgregor, & Begley,
9.3 Nurses and support workers for the care of older people

Several significant issues are becoming apparent in the nursing services and workforce designated for the care of older people. An Australian report on aged-related residential care revealed inadequate support services and nursing workforce to meet the increased demand from older people in Queensland; a state that has experienced a huge growth in the number of retirees (Eley, et al., 2007). In the USA, 45 percent of community-based support services provided by registered nurses were to people in aged 65-85, however less than half the undergraduate nursing programmes provided adequate education and clinical preparation in the care of older people (Tassone Kovner, Mezey, & Harrington, 2002). In New Zealand, retirement of an ageing nursing workforce, along with external migration and insufficient graduate numbers to counter the shortfall, has created significant problems for nursing services (North, 2011). These findings expose the very real problem faced by the healthcare sector of an underprepared nursing profession with insufficient numbers to meet the growing demand for their services.

Professional development for nurses employed in the aged-care sector is also an issue with barriers, such as the cost of fees and travel, and a lack of staff substitutes to allow nurses leave from clinical responsibilities preventing attendance at education sessions (Eley, et al., 2007). The aged care sector has not been a popular employment option for registered nurses nor is it funded well for unskilled workers. An environment of dissatisfaction with pay and work hours, and staffing shortages all contributed to a stressful workplace and inevitably lead to difficulties in recruitment and retention of personnel (Eley, et al., 2007). Findings from this study revealed the challenges participants encountered in accessing funded support services or attempting to engage suitable people to assist the older person with their daily activities. The appropriateness of disability support services provided, especially for older people with cognitive impairment or dementia, as reported by the participants, infers a lack of understanding of the special needs of these people. The delivery of care in the community requires an abundant resource of appropriately educated nurses and support workers which, currently, is not apparent (North, 2011; Tassone Kovner, et al., 2002). Given previous findings on the positive effects of home visiting by trained health professionals on morbidity and mortality rates and reduction in residential care admission, it is obvious that an educated workforce is needed to support older people living in the community (Andersson Svidén, et
Implications and Recommendations

al., 2004; Kuzya, et al., 2006). It is inevitable that the nursing and support workforce will struggle to meet the needs of a growing population of older people with varying physical and cognitive conditions.

Not all home based services entail deployment of qualified health workers such as registered nurses, as they often address basic care that can be delivered by support workers, such as house work, meal preparation, and hygiene needs. These semi-skilled workers are generally trained on the job to provide uncomplicated care, usually under the direction of a qualified nurse. It is known that support workers are generally women, poorly educated, amongst the lowest paid, and as a consequence hold a position of low status in the health care sector (Jorgensen, et al., 2009; Stone & Wiener, 2001). One of the major problems is the value society places on a service industry that uses low paid workers to deliver support to a non-productive sector of the community. Recommendations in the USA include policies to promote the supply of personnel, invest in education and licensing of support workers, and to raise wages, all with the aim of elevating the sector to a more valued component of society (Stone & Harahan, 2010). The UK has also begun developing the support worker role as acknowledgement of the complex needs and high dependency of many older people (Eyers & Bryan, 2006). In New Zealand, support workers favoured the notion of national, generic paid training programmes and certification to encourage a more positive attitude toward their role, however reported having difficulty attending training sessions due to a lack of funding for travel and associated costs (Jorgensen, et al., 2009). Training programmes would no doubt enhance client outcomes and bring about more standardised care for older people.

The following recommendations arise from the findings of this study with a focus on the key issues of planning for retirement and disability support services for the impending older population and their families. Also future research opportunities identified from this study are discussed.
9.4 Recommendations

The following recommendations address the key findings of the study and specify critical points for government agencies charged with determining policy, planning for and funding services, education of the nursing and support workforce, provision of sufficient resources to support the caregiver, and informing the public of entitlements for support services.

**Improved access to appropriate disability support services for older people**

It is recommended that the Disability Support Service and Needs Assessment Coordination Service provide more readily available information to older people and their caregivers on support services for older people living in the community. Such information should clarify entitlement and access to support services including assessment of need and means-testing. Information on this service could be offered through General Practitioners, public hospitals and other healthcare providers such as private consultants and physiotherapists. Providing such information would allow the caregivers of older people to access assistance appropriate to the older person’s needs while still enabling them to remain living in the community.

It is also recommended that the Disability Support Services be reviewed with consideration for a more flexible provision of support that meets the individual needs of the older person. It is apparent that the need of support for people with cognitive impairment differs considerably from those with physical disabilities and the services provided must reflect these differences to ensure they are appropriate.

**Suitable and affordable housing for older people**

It is recommended that the Government takes an active role in building suitable and affordable rental housing for older people and encouraging property developers to make provision for aged-appropriate housing within new urban developments. Such an action would involve designating more land for residential development while simultaneously introducing legislation that requires developers to include a specified number of affordable, single-level dwellings suitable for older people with actual or potential mobility deficits. Government funded housing projects would also provide employment for trades people, apprenticeship opportunities for young people, and together stimulate economic development.
Implications and Recommendations

Support of family caregivers of older people
It is recommended that the government and the Department of Labour review the section of the Holidays Act 2003 that makes provision for sick leave. Changes could include provision for employees, who are the acknowledged caregiver of an older person with disabilities, to have a defined period of absence from the workplace to provide support as required.

Recognition of the aged-care nursing and carer workforce
It is recommended that the Ministry of Health and government review both the wage structure and training programmes for nursing and carer workforce as a means of ensuring a service that is appropriate to the needs of the growing number of older people. In particular, attention must be made to the relationship between training that acknowledges the special needs of older people, the outcomes for these people, and valuing the supporting role. It is also recommended that the government reviews the current and potential problems of this workforce capability and devises policies that will seek to redress these imbalances.

Financial planning for retirement
Encouraging the population to take more responsibility for financial planning for their future retirement needs will ease some of the burden on the government. It is recommended that the New Zealand Parliament employs a non-partisan approach to debate and consult with the public thus enabling an equitable process is utilised regarding the structure and implementation of a compulsory superannuation scheme. To ensure fairness to all employees and self-employed workers the scheme should not have an opt-out clause; however it will necessitate an increase in the basic wage to cover employee contributions, especially for lower income earners. Reintroduction of a compulsory superannuation scheme would establish an accumulating fund with the capacity to address New Zealand’s social commitment to retirees both now and into the future and ensure age-related poverty is limited.

9.5 Future Research opportunities
Further research in the area of the sources and funding of future support needs for impending numbers of older people is needed. Such research would provide valuable information for government agencies charged with funding and supplying support services to older people as well as informing the population of their personal responsibility in planning for old age.
The following factors would address the knowledge deficits in relation to the current mid-life adults and those transitioning into retirement, their potential ageing needs and support structures:

1. effects on the caregiver of delaying life plans to support an older person;
2. reasons for the older person’s preferences in family caregivers;
3. financial preparedness for retirement;
4. housing preferences, suitability and affordability;
5. potential for functional support from family members; and
6. nursing and support workforce education, remuneration and retention

Additionally, a longitudinal study of the current mid-life to 65 year olds would also provide important data which could be extrapolated to gain a picture of the developing needs of the ageing population. Gaining data that could be generalised to the wider population would provide greater clarity to aid government policy makers, and the planning and funding designed to attend to the specific requirements and expectations of the impending population of older people over the next 40 years and beyond.

Summary
As an exploratory study many issues have been identified that highlight potential problems for those focused on addressing the needs of an ageing population. The findings have implications for the New Zealand government, particularly funding of superannuation and aged-care support services, and the nursing and support worker education and roles. By 2030, 25 percent of the population will be over 65 years; significant projections that foreshadow the need for considerable planning to face the challenges that will arise. It cannot be assumed that all of this large cohort will either require assistance as they age or be expected to achieve a level of health and fitness that would preclude them from requiring support at the latter end of life. People are more likely to experience progressively disabling chronic illnesses as they age, especially in the last few years of life. There are inferences for the current mid-life adults to preserve their health and address financial planning for their impending retirement years. For the families and friends of older people there will be a greater expectation of providing functional support to meet the likely shortfall between need for assistance and government-funded support service provision.
Office of the Vice-Chancellor  
Ethics and Biological Safety Secretariat  

UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE

12 June, 2008
MEMORANDUM TO: 
Mrs Helen Malcolm 
School of Nursing

Re: Change to application

I wish to advise you that the Committee met on 11 June, 2008 and reviewed the request for change to your application titled "Growing older in New Zealand: Perceptions and expectations of today's adults regarding their ageing and future support." (Our Ref. 2008 / 164).

The Committee approved the change.

If the project changes significantly you are required to resubmit your application to the Committee for further consideration.

In order that an up-to-date record can be maintained, it would be appreciated if you could notify the Committee once your project is completed.

Please contact the Chairperson if you have any specific queries relating to your application. He and the members of the Committee would be most happy to discuss general matters relating to ethics provisions if you wish to do so.

Lana Lon  
Executive Secretary  
University of Auckland Human Participants Ethics Committee

c.c. Head of Department, School of Nursing

1. All communications with the committee regarding this application should indicate this reference number - (2008/164).
2. At the end of the three years, or earlier if the project is completed, you are requested to advise the Committee of its completion.
Participant's Information Sheet: Focus Group
Growing older in New Zealand

Principal Research: Helen Malcolm
I have an interest in older people’s health and how they cope with ageing. I am undertaking this study as a PhD candidate with the University of Auckland.

You are invited to take part in a study to find out how today’s ‘mid-life’ adults regard their growing older, and the support which they might need. Taking part is voluntary (your choice).

What is the purpose of the study?
Although there is considerable research on the impact of ageing and implications for other family members, little is known about the current mid-life adult population in New Zealand regarding how they see their own ageing and possible needs. Considering future needs and choice for support is important as this generation of New Zealanders grows older.

What is involved?
The study involves participating in a small group discussion, where you are invited to share your thoughts and experiences related to growing older and caring for older relatives or friends. The approximate time involved will be 1½ hours and the meeting will take place close to the area you live. A tape-recorder will be used to record the discussion and you will be offered a copy of the written tape copy for further comment should you wish to do so.

What are the benefits?
There are no direct benefits for you other than the opportunity to share your thoughts about the topic. However, the study findings will be used to develop further research on the topic which may provide information useful to planners of future healthcare, housing and support for older people.

What are the potential risks and discomforts?
There are no anticipated risks to you in participating in this study, but should any concerns regarding ageing and support needs arise for you, it is recommended that you discuss these concerns with your doctor, nurse, family, support network or contact the office of the National Health and Disability Services Consumer Advocate.

Confidentiality
Your identity will remain confidential, known only to the researcher and other focus group participants. Group members will be encouraged to respect the views and comments of others in the group and maintain the confidentiality of other participants. Your comments will be treated in confidence, with information held securely in the researcher’s office at the School of Nursing, University of Auckland. Access to the information shared by the group is restricted to the researcher and research supervisors only. The written report will in no way identify you as a participant. Participant information and taped focus group sessions will be stored securely in my office at the University of Auckland and retained for six years following completion of the study.

Withdrawal from the study
Your participation in this study is voluntary and you will not be pressured in any way to comply. You have the choice of not answering specific questions as desired and are free to
withdraw from the study at any time if you wish to up until 30th June, 2010, without explanation. However, as the tape-recordings will not identify you directly, removing your comments from the group discussion will not be possible.

Results
On completion of the study, you will be sent a copy of the Summary (a brief description of the study and its findings).

Further research
The researcher would like to undertake a small number of face-to-face interviews to further explore the issues raised in the Focus Group. If you would like to be considered to take part in an interview, please indicate this on the consent form.

For further information:

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<th>Primary Researcher details:</th>
<th>Head of Department:</th>
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<tbody>
<tr>
<td>Helen Malcolm,</td>
<td>Associate Professor Judy Kilpatrick</td>
</tr>
<tr>
<td>Tel: [09] 3737599 extn. 87934</td>
<td>Tel: 09 3737599 extn. 87563</td>
</tr>
<tr>
<td>Te: [09] 5289636</td>
<td><a href="mailto:j.kilpatrick@auckland.ac.nz">j.kilpatrick@auckland.ac.nz</a></td>
</tr>
<tr>
<td><a href="mailto:h.malcolm@auckland.ac.nz">h.malcolm@auckland.ac.nz</a></td>
<td>School of Nursing</td>
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<tr>
<td>School of Nursing</td>
<td>The University of Auckland</td>
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<tr>
<td>The University of Auckland</td>
<td>PO Box 92019</td>
</tr>
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<td>PO Box 92019</td>
<td>Auckland</td>
</tr>
</tbody>
</table>

For ethical concerns contact: The Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Room 005 Alfred House Nathan House, 24 Princes Street, Private Bag 92019, Auckland. Tel: 09 3737599 extn. 87830

For any other concerns contact the Principal Research Supervisor:
Associate Professor Dr. Robyn Dixon, Director of the Centre for Child and Family Research, School of Nursing, Grafton Campus, Private Bag 92019, Auckland. Tel: 09 3737599 extn. 87388 OR
Dr Diane ö (2nd Supervisor), School of Nursing, University of Auckland, Private Bag 92019, Auckland. Tel: 09 3737599 extn. 82245

Research approved by The University of Auckland Human Participants Ethics Committee on 11 June, 2008 (Ref. 2008/164).

Thank you for considering participating in this research study.
Appendix 3

Participant’s Information Sheet: Individual Interview
Growing older in New Zealand

Principal Research: Helen Malcolm

You are invited to take part in a study to find out how today’s ‘mid-life’ adults regard their growing older, and the support which they might need. Taking part is voluntary (your choice).

What is the purpose of the study?
Although there is considerable research on the impact of ageing and implications for other family members, little is known about the current mid-life adult population in New Zealand regarding how they see their own ageing and possible needs. Considering future needs and choice for support is important as this generation of New Zealanders grows older.

What is involved?
The study involves participating in an interview where you are invited to share your thoughts and experiences related to growing older and caring for older relatives or friends. The approximate time involved will be 1½ hours, with the possibility of extending this time if this is suitable to you. The interview will take place at a venue suitable to both you and the researcher. A tape-recorder will be used to record the discussion and further information gathered on a “Family Tree” form. Should you feel uncomfortable at any time and wish the tape-recorder to be stopped, the researcher will comply with your wishes. You will be offered a written copy of the tape recording for your further comment.

What are the benefits?
There are no direct benefits for you other than the opportunity to share your thoughts about the topic. However, the study findings will be used to develop further research on the topic which may provide information useful to planners of future healthcare, housing and support for older people.

What are the potential risks and discomforts?
There are no anticipated risks to you in participating in this study, but should any concerns regarding ageing and support needs arise for you, it is recommended that you discuss these concerns with your doctor, nurse, family, support network or contact the office of the National Health and Disability Services Consumer Advocate.

Confidentiality
The information you share with the researcher will be held securely in the researcher’s office at the School of Nursing, University of Auckland. Access to the information is restricted to the researcher and research supervisors only. Your identity will remain confidential, known only to the researcher. The written report will in no way identify you as a participant.

Withdrawal from the study
Your participation in this study is voluntary and you will not be pressured in any way to comply. You have the choice of not answering specific questions as desired and are free to withdraw from the study at any time if you wish to up until 30th June, 2010, without explanation.
Results
On completion of the study, you will be sent a copy of the Summary (a brief description of the study and its findings).

If you have any queries or concerns about your rights as a participant in this study you may wish to contact a Health and Disability Services Consumer Advocate, telephone: 0800 37 77 66.

For further information:

<table>
<thead>
<tr>
<th>Primary Researcher details:</th>
<th>Head of Department:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helen Malcolm,</td>
<td>Associate Professor Judy Kilpatrick</td>
</tr>
<tr>
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<tr>
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<td>Auckland</td>
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</tr>
</tbody>
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For ethical concerns contact: The Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Room 005 Alfred House Nathan House, 24 Princes Street, Private Bag 92019, Auckland. Tel: 09 3737599 extn. 87830

For any other concerns contact the Principal Research Supervisor: Associate Professor Dr. Robyn Dixon, Director of the Centre for Child and Family Research, School of Nursing, Grafton Campus, Private Bag 92019, Auckland. Tel: 09 3737599 extn. 87388 OR Dr Diane Jorgensen (2nd Supervisor), School of Nursing, University of Auckland, Private Bag 92019, Auckland. Tel: 09 3737599 extn. 82245

Research approved by The University of Auckland Human Participants Ethics Committee on 11th June, 2008 (Ref. 2008/164).

Thank you for considering participating in this research study.
Are you aged between 45 and 65 years old?

Have you or are you supporting your parents or grandparents as they grow older? Would you be prepared to talk about your experiences for a study on your future ageing and expected support needs in New Zealand?

For more information, please contact Helen Malcolm on 09 373 5999 ex 879340 or growing.older@auckland.ac.nz
Are you aged between 45 and 65 years old?

- Have you or are you supporting your parents, grandparents or friends as they grow older?

- Would you be prepared to share your experiences in a small group of people having a similar experience?

- The purpose of the group meeting is to discuss people’s views on future ageing and expected support needs in New Zealand.

For more information, please contact
Helen Malcolm,
Tel: 09 373 7599 ext 87934
e-mail: growing.older@auckland.ac.nz

Research approved by The University of Auckland
Human Participants Ethics Committee on 29/05/2008
AGEING IN NEW ZEALAND FOCUS GROUP

Are you aged between 45 and 64 years and have cared for an older person?

Have you or are you supporting your parents, grandparents of friends as they grow older?

Would you be prepared to share your experiences in a small group of people having a similar experience?

If so, you are invited to take part in a focus group to discuss your experiences of supporting an older person and also how you are planning for your own future ageing.

What is the purpose of the study?
Although there is considerable research on the impact of ageing and implications for other family members, little is known about how the experience of caring for older relatives or friends influences people’s planning and expectations of their own ageing needs. Considering future needs and choice for support is important for the increasing population of older people in New Zealand.

What is involved?
The research involves participating in a focus group discussion with other people, aged between of 45 and 64 years, who have also experienced the role of caring for an older person. A focus group generally comprises between five and nine people and is a place to freely discuss specific issues of interest to all participants.

Food and beverages will be provided.

If you are interested in learning more please contact the researcher Helen Malcolm:

Phone 923 7934 OR email h.malcolm@auckland.ac.nz

If you are interested in participating, Helen will post you a copy of the information sheet and consent form for you to consider, and discuss suitable dates, times and venue for the focus group.

Thank you for considering participating in the focus group.

The study has received ethics approval from the University of Auckland Human Participants Ethics Committee (Ref 208 / 164).
The Chair,
University of Auckland Human Ethics Committee,
University of Auckland,
Private Bag 92019,
Auckland Mail Centre 1142,
Auckland.

Dear Sir/Madam,

Re: Ethics approval 2008 / 164
Growing older in New Zealand: Perceptions and expectations of today’s adults regarding their ageing and future support.

I am writing with regard to the above approval number and to inform the committee of my intention to extend the data collection by holding a focus group exclusively for Māori participants. Despite varied recruitment processes for the previously conducted focus groups, there was no participation by people who identified as Māori.

I consider it is important that the Māori voice is included in the study which looks at the experiences of caring for older family / whanau members and how these experiences are shaping the thoughts and expectations of the current 40-64 year olds regarding how their future ageing needs might be met.

A meeting in January with Associate Professor Papaarangi Reid endorsed the importance of having the Māori viewpoint on the topic. Subsequent to the meeting, Dr. Lorna Dyall, Senior Lecturer, Medical Te Kupenga Hauora Māori School of Population Health, agreed to recruit participants for the focus group and facilitate the Hui. I have also discussed with Lorna the need to identify a suitable Māori person to guide the data analysis. There has been agreement among potential participants to have an audio recording made of the Hui and once this is transcribed copies will be made available to all participants for their consideration. Any ensuing changes will be incorporated into the data for analysis. On completion of the hui data analysis I will report back to Associate Professor Reid on the outcomes of the focus group and discuss the options for dissemination of the information.

Attached is a letter from Assoc. Prof. Reid supporting the need for the focus group, and the facilitation process utilised.

Yours sincerely,

Helen Malcolm,
Lecturer,
School of Nursing,
Faculty of Medical and Health Sciences, University of Auckland.
31 March 2010

University of Auckland Human Participants Ethics Committee
Level 3, Building 438,
76 Symonds Street.
Auckland

Tēnā koutou, tēnā koutou, tēnā tātou katoa,

Re: Helen Malcolm

Title: Growing older in New Zealand: Perceptions and expectations of today’s adults regarding their ageing and future support

Helen Malcolm has consulted with Office of the Tumuaki at the Faculty of Medical and Health Sciences (FHMS), University of Auckland about the above project, and the ethics application. We have read the application and advised accordingly on aspects of Māori responsiveness.

We have no outstanding issues after this consultation and support the proposal before your committee.

Noho ora mai

Associate Professor Papaarangi Reid
Tumuaki
Office of the Vice-Chancellor
Ethics and Biological Safety Administration

UNIVERSITY OF AUCKLAND
HUMAN PARTICIPANTS ETHICS COMMITTEE

19 April 2010

MEMORANDUM TO:
Mrs Helen Malcolm / Mrs Helen Malcolm
School of Nursing

Re: Application for Ethics Approval (Our Ref. 2008 / 164)

The Committee met on 14-April-2010 and considered your request for amendment for your project titled "Growing older in New Zealand: Perceptions and expectations of today's adults regarding their ageing and future support."

The Committee approved the following amendment(s):

Extend the data collection by holding a focus group exclusively for Maori participants.

Note: Approval of this change does not constitute an extension of the project approval period.

The expiry date for this approval is 11/06/2011.

If the project changes significantly you are required to resubmit a new application to the Committee for further consideration.

In order that an up-to-date record can be maintained, it would be appreciated if you could notify the Committee once your project is completed.

Please contact the Chairperson if you have any specific queries relating to your application. The Chair and the members of the Committee would be most happy to discuss general matters relating to ethics provisions if you wish to do so.

All communications with the UAHPEC regarding this application should indicate this reference number - 2008 / 164

Lana Lon
Executive Secretary
University of Auckland Human Participants Ethics Committee
c.c. Head of Department / School, School of Nursing

Mrs Helen Malcolm
Appendix 10

Consent Form: Focus Group
Growing older in New Zealand

Principal Researcher: Helen Malcolm

This form will be held for a period six years

• I ………………………………………………………………….. have read the Information Sheet explaining the research on growing older in New Zealand and I have understood what this research entails.
• I have had the opportunity to discuss the study and receive clarification as desired.
• I understand that taking part in this study is my choice and I may withdraw from the study at any time.
• I understand that the information I offer will be reported in a way that does not identify me as the source.
• I have had time to consider whether to take part in the study.
• I know whom to contact if I have any questions about the study.
• I consent to take part as a voluntary participant in the study.
• I consent to audio-tape recording the group discussion.

Signature: ________________________________
Address: ____________________________________
_________________________________________
Telephone:_________________

• I am happy to be contacted with regard to participation in a face-to-face interview (please circle)

Yes       No

Research approved by The University of Auckland Human Participants Ethics Committee on 11 June, 2008 (Ref. 2008 / 164)
Consent Form: Individual Interview  
Growing older in New Zealand

Principal Researcher: Helen Malcolm  This form will be held for a period six years

- I ………………………………………………………………….. have read the Information Sheet explaining the research on growing older in New Zealand and I have understood what this research entails.
- I have had the opportunity to discuss the study and receive clarification as desired.
- I understand that taking part in this study is my choice and I may withdraw from the study at any time.
- I understand that the information I offer will be reported in a way that does not identify me as the source.
- I have had time to consider whether to take part in the study.
- I know whom to contact if I have any questions about the study.
- I consent to take part as a voluntary participant in the study.
- I consent to audio-tape recording the interview.

Signature:  ________________________________
Address:  ________________________________

Telephone:  ________________

Research approved by The University of Auckland Human Participants Ethics Committee on 11 June, 2008 (Ref. 2008 / 164).
Focus Group Guideline and Discussion Prompts:
Growing older in New Zealand

Focus groups are recognised as a dynamic means of exploring an area of interest with open
discussion stimulating participant interaction. The researcher (or group moderator) has the
role of setting up the group process, providing guidelines on group behaviour and
confidentiality, and initiates and maintains the discussion through questions or prompts. The
following guidelines and prompts will be used to manage the group process.

Moderator Guidelines:

- Refreshments (non-alcoholic) will be provided to establish a relaxed atmosphere.
- Participants will be invited to introduce themselves and provide a brief explanation for
  why they chose to be involved in the focus group.
- Description of the purpose of the focus group and the overall research project.
- Outline of how the group discussion will proceed, recording data, and duration of the
  meeting.
- Guidelines on respecting participants' viewpoints and listening as others speak.
- Guidelines on confidentiality of information shared during the focus group discussion.
- Reiteration of their rights as research participants including the right to withdraw.

Discussion Prompts:

- Tell me about your experiences of caring for an older relative?
- Reflecting on this experience, would you change any aspect of this situation?
- What was the most positive aspect of this experience for you? And for your older
  relative?
- What was the most difficult aspect of this experience for you? And for your older
  relative?
- Did your own children or younger family members participate in supporting the older
  person?
- Try to imagine yourself aged 65 years or more. What would the picture be for you?
- Tell me how you think you will manage your older years?
- Who do you think might help you when you get to be over 65 years old?

Closing the discussion:

- At the end of the discussion, time will be made for group debriefing and the participants
  will be encouraged to contact the researcher should they wish to express further views
  on the topic of interest.
- Participants will be reminded that if any personal concerns arise from the discussion,
  they are encouraged to speak with family members, usual confidante, health
  professional or contact the office of the Health and Disability Advocacy Service.
Individual Interview: Conversation Prompts
Growing older in New Zealand

During the interview I will use the “Family Tree” document to explore the participants’ position in the context of their family and to initiate their talking about the older family members whose ageing they have observed and the support they are aware that the older person has received or needed. The process of using the family tree is to establish the complexity of the relationships within the participants’ multi-generational family, especially family support needed and provided by relatives and other agencies, and the communication among various relatives to achieving the older person’s support needs. The following conversation prompts will be used to initiate the discussion related to this process as a means of gathering data both by simultaneous audio recording of the discussion and writing on the family tree.

- Show me where you would fit on this family tree related to your brothers and sisters?
- Tell me about your brothers and sisters and where they are living now?
- Tell me about your parents: are they still alive and do they need support?
- Can you tell me about other older relatives or friends, apart from your parents who you are supporting now or maybe in the future?
- Tell me about your grandparents: are they still alive and do they need support?
- Are there other relatives in this generation, apart from your grandparents who you are supporting now or potentially in the future?
- Tell me about the support you provide for your older relative(s)?
- Do your siblings also provide support for your older relatives(s)?
- Do other family members, apart from your siblings, provide support for your family member(s)?
- How do you decide who will meet each aspect of the older person’s needs?
- Do you feel the older person’s support needs are being meet fairly by the family members involved?
- Can explain to me your ideas of how you would like your older years to be?
- Knowing about the ageing needs of your older relatives, have you considered your own potential needs as you grow older?
- Have you thought about how these needs might be met?
- If you were unable to manage without help for such things as housework, gardening, shopping and cooking, have you considered who will help you with these things?
- Do you expect your children to help you in any way as you grow older?

These conversation prompts will in no way limit the participants in what they wish to talk about. The principal investigator will be sensitive to allowing them the opportunity to discuss issues of importance to them.
Transcriber Confidentiality Agreement
Growing older in New Zealand

I, Janet Templeton, agree to maintain the confidentiality of participants’ audio-taped interviews in the research conducted by Helen Malcolm.

I agree to:
- maintain security of the audio-tapes, computer access, and USB Flash drive during the period in which I am transcribing the tapes.
- not discuss details of the interviews with anyone other than the researcher.
- return all material to the researcher on completion of transcribing the audio-tapes.
- delete all transcribed data from my computer on completion of the transcribing process.

Signed: [Signature] (Transcriber) Date: 20.10.08

Signed: [Signature] (Researcher) Date: 20.10.08
Perceptions and expectations of ageing and future support:
Survey questionnaire

Please select the answer that best describes your situation, memories, thoughts, feelings and experiences. Some questions seek a yes or no answer while other questions provide a range of options. There is also provision for you to make comments.

YOU and YOUR LIFESTYLE: The following questions seek details about you and your circumstances and lifestyle.

Please select options for each question by circling the most appropriate answer before moving onto the next.

1. I am         male  female

2. The group that represents my age is:  40-44    45-49       50-54          55-59 60-64

3. The ethnic group I MOST identify with: (circle one) Māori Pacific Island Indian
New Zealand European Asian Other (specify)____________________

4. The other people who live in my household are: Select as many as apply to you
Husband  Wife  Partner  Children  Parents
Grandparents  Grandchildren  Friends Flatmates I live alone
Other (specify) ___________________________

5. The following number of children live in my home: (insert number of children in this age bracket)
0-5 years _______  6-12 years _______  13-17 years _______  18+ years _______

6. I own the property I live in (freehold, with mortgage or in a family trust) Yes No

7. I rent the property I live in (State or privately owned) Yes No

8. My MAIN occupation is best described as: (Select ONE)
Full-time paid work Part-time paid work Homemaker Self-employed Unemployed
9. I would like to be in paid employment but can’t because: (Select as many as apply to you)
   I am caring for a young family member        I am caring for an older family member
   Other (specify) _________________________________________ Not applicable

10. My current state of health is: Please circle
    Excellent  Very Good  Average  Poor  Very poor

11. My current level of fitness is: Please circle
    Excellent  Very Good  Average  Poor  Very poor

12. Is your mother alive?  Yes  No
    Please tick your option
    Excellent  Very Good  Average  Poor  Very poor
    My mother’s state of health is: □ □ □ □ □
    My mother’s level of independence is: □ □ □ □ □

13. Is your father alive?  Yes  No
    Please tick your option
    Excellent  Very Good  Average  Poor  Very poor
    My father’s state of health is: □ □ □ □ □
    My father’s level of independence is: □ □ □ □ □

14. I have ____ (number) living brothers.
15. I have ____ (number) living sisters.

SUPPORTING OR CARING FOR AN OLDER PERSON:
The following questions seek answers about your experience of assisting an older person. If you currently support or have previously supported more than one person, answer the questions in relation to the person you supported most closely. If you have not supported or cared for an older person, go directly to Question 29.

16. When you started to provide assistance the older person was aged: Select ONE
    65-69  70-74  75-79  80-84  85-89  90 +

17. The older person is/ was your: (Select ONE)
    Mother  Father  Mother-in-law  Father-in-law  Grandmother
    Grandfather  Aunt  Uncle  Family Friend  Other (specify)__________
18. You assist or have assisted the older person with the following:

<table>
<thead>
<tr>
<th>Select and tick frequency</th>
<th>Daily</th>
<th>Weekly</th>
<th>Fortnightly</th>
<th>Monthly</th>
<th>Occasionally</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bathing/Dressing</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Meal preparation</td>
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<td>□</td>
<td>□</td>
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<td>□</td>
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<td>□</td>
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<td>□</td>
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<td>□</td>
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<tr>
<td>Gardening</td>
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<td>□</td>
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<td>□</td>
<td>□</td>
<td>□</td>
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<tr>
<td>Driving to appointments</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Finances</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
<tr>
<td>Other (specify type of assistance and frequency offered)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

19. On a scale of 1 (strongly disagree) to 5 (strongly agree) please indicate the extent to which you agree with the following statements:

<table>
<thead>
<tr>
<th>Circle option</th>
<th>Strongly disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I assist/assisted the older person because I love them</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>I assist/assisted the older person through a sense of duty</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>I assist/assisted the older person because I felt guilty</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>I assist/assisted the older person because my family expects me to</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>I assist/assisted the older person because I sense society expectations</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>I assist/assisted the older person because no-one else was available</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>I assist/assisted the older person because they expected me to</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>

20. **Most of the time** I am/was pleased to provide assistance to the older person: **Circle option**

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>
21. I resent the amount of time providing assistance to the older person has/had on my daily life:

Circle option

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>

22. Providing assistance to the older person does/did impact on time I had to spent with my family:

Circle option

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>

23. Does/did the older person receive assistance from other family members?  Yes  No

If you answered No, please go to question 25.

24. Do/did some family members offer more support than others?  Yes  No

25. On a scale of 1 (strongly disagree) to 5 (strongly agree) please indicate the extent to which you agree/disagree with the following statements about assistance from family members.

Circle option

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

They live too far away to provide assistance 1 2 3 4 5
Their own family commitments limit time to assist 1 2 3 4 5
They are unwilling to provide assistance 1 2 3 4 5
Their employment/training commitments limit time to assist 1 2 3 4 5
Their financial constraints limit their ability to assist 1 2 3 4 5
They are not interested in providing assistance 1 2 3 4 5
Other (specify)
26. On a scale of 1 (strongly agree) to 5 (strongly disagree) please indicate the extent to which you agree/disagree that the following exerted pressure on you to offer assistance to the older person:

**Circle option**

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other relatives</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>Health professionals</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>Religious /cultural groups</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>The older person</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>Societal expectations</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>Other (specify)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

27. If the older person receives/received government funded support, what activities does/did the funding support? (Select as many as apply)

Shopping Bathing/Dressing Meal preparation Housework Visual aids
Hearing Aids Getting to appointments Mobility aids Not applicable
Other (Specify) ______________________________________

28. If the older person does/did not receive government funded support, you understand this to be because:

**Circle option**

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>They are/were unaware government support was available</td>
<td></td>
<td></td>
</tr>
<tr>
<td>They expect/expected the family to provide support</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>The older person is/was ineligible based on income</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>The older person is/was unwilling to accept government support</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>The older person is/was unwilling to accept strangers’ support</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Other (Specify) ________________________________</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**PLANNING FOR YOUR OWN AGEING:**
The following questions seek answers about planning for your own ageing years.

29. I have contributed to a superannuation fund Yes No

30. I have made provision for my retirement Yes No
31. Responsibility for providing the following assistance to meet my old age needs should be:

Select ONE option per service

<table>
<thead>
<tr>
<th>Service</th>
<th>Mine</th>
<th>OR</th>
<th>My Family</th>
<th>OR</th>
<th>Government</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housework</td>
<td>☐</td>
<td></td>
<td>☐</td>
<td></td>
<td>☐</td>
</tr>
<tr>
<td>House maintenance</td>
<td>☐</td>
<td></td>
<td>☐</td>
<td></td>
<td>☐</td>
</tr>
<tr>
<td>Gardening</td>
<td>☐</td>
<td></td>
<td>☐</td>
<td></td>
<td>☐</td>
</tr>
<tr>
<td>Bathing / dressing assistance</td>
<td>☐</td>
<td></td>
<td>☐</td>
<td></td>
<td>☐</td>
</tr>
<tr>
<td>Mobility aids / rails etc.</td>
<td>☐</td>
<td></td>
<td>☐</td>
<td></td>
<td>☐</td>
</tr>
<tr>
<td>Transport to medical appointments</td>
<td>☐</td>
<td></td>
<td>☐</td>
<td></td>
<td>☐</td>
</tr>
<tr>
<td>Assistance with shopping</td>
<td>☐</td>
<td></td>
<td>☐</td>
<td></td>
<td>☐</td>
</tr>
<tr>
<td>Payment for medical care</td>
<td>☐</td>
<td></td>
<td>☐</td>
<td></td>
<td>☐</td>
</tr>
<tr>
<td>Pay for full-time residential care</td>
<td>☐</td>
<td></td>
<td>☐</td>
<td></td>
<td>☐</td>
</tr>
<tr>
<td>Pay for full-time care in the community</td>
<td>☐</td>
<td></td>
<td>☐</td>
<td></td>
<td>☐</td>
</tr>
<tr>
<td>Other (specify)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

You may regard yourself as too young for the following questions however consider them with a view to your possible future needs.

32. Are any of the following factors likely to influence your choice of support in your old age? Circle option

<table>
<thead>
<tr>
<th>Factor</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I do not want to be a burden to family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My family’s work/child commitments and time available to support me</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I want to retain my independence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My family do not live near enough to offer practical support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My family cannot afford to provide support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I do not have a good relationship with family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have no close family to offer assistance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have no contact with family</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Comments:____________________________________________________________________________
33. On a scale of 1 (least important) to 5 (most important) please indicate how important the following reasons will be in determining where you live as you grow older. **Circle option**

<table>
<thead>
<tr>
<th>Reason</th>
<th>Not important</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>Most important</th>
</tr>
</thead>
<tbody>
<tr>
<td>To live closer to family</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>To have a low maintenance property</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>To have a home smaller than my current home</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>To live in a retirement village</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>To live close to healthcare services</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>To live close to shops</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>To live close to public transport</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>To live in a warmer climate</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

34. On a scale of 1 (strongly disagree) to 5 (strongly agree) please indicate your response to the following statement:

*If I choose to move closer to my family it will be for the following reason:*

**Circle option**

<table>
<thead>
<tr>
<th>Reason</th>
<th>Strongly Disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>To assist with grandchildren</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>To receive companionship</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>To receive assistance from family</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>

Comments:__________________________________________________________________

35. On a scale of 1 (very unlikely) to 5 (very likely) how likely would you be to accept the following assistance from family to meet your needs as you grow older? **Circle option**

<table>
<thead>
<tr>
<th>Assistance</th>
<th>Very Unlikely</th>
<th>Very Likely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Housework</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>House maintenance</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>Gardening</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>Bathing / dressing assistance</td>
<td>1 2 3 4 5</td>
<td></td>
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<td>Payment for mobility aids / rails etc.</td>
<td>1 2 3 4 5</td>
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<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>Assistance with shopping</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>Payment for medical care</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>Payment for full-time care</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
</tbody>
</table>

36. The person **MOST** likely to assist you with your personal needs as you grow older is your:

<table>
<thead>
<tr>
<th>Relationship</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Daughter(s)</td>
<td>Son(s)</td>
<td>Niece(s)</td>
<td>Nephew(s)</td>
<td>Granddaughter(s)</td>
<td></td>
</tr>
<tr>
<td>Grandson(s)</td>
<td>Neighbour(s)</td>
<td>Other (specify)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

207
37. The person **MOST** likely to assist you with your household needs as you grow older is your:

Daughter(s)  Son(s)  Niece(s)  Nephew(s)  Granddaughter(s)
Grandson(s)  Neighbour(s)  Other (specify)

38. The person **MOST** likely to assist you with your financial needs as you grow older is your:

Daughter(s)  Son(s)  Niece(s)  Nephew(s)  Granddaughter(s)
Grandson(s)  Neighbour(s)  Other (specify)

39. When you are 75 years old, where do you expect to be living and how do you think your support needs will be met?

_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________

Thank you for completing the Ageing in New Zealand survey.

**Principal Researcher details:**
Helen Malcolm,
Lecturer and PhD Candidate
Tel: [09] 923 7934 or h.malcolm@auckland.ac.nz
School of Nursing, The University of Auckland, Private Bag 92019, Auckland
Perceptions and expectations of ageing and future support:  
Participant Information Sheet

Are you aged between 40 and 64 years of age?

If so, you are invited to take part in a survey to find out about experiences of supporting older relatives or friends (if you have done so), and how you are planning for or managing your own ageing. Participation is voluntary.

Principal Researcher: Helen Malcolm  
As a postgraduate student with the University of Auckland, I am studying how the ageing needs of the older people of New Zealand are being meet now and what the anticipated needs are for the future support of the ageing population. I am undertaking the research toward fulfillment of the requirements of my PhD dissertation.

What is the purpose of the study?  
Although there is considerable research on the impact of ageing and implications for other family members, little is known about how the experience of caring for older people influences individual’s planning and expectations of their own as they age. Considering future needs and choice for support is important for the increasing population of older people in New Zealand.

What is involved?  
The research involves completing a questionnaire which seeks the views of people between the 40 and 65 years of age. The questions cover a range of subjects related to your current lifestyle, observation and experience of caring for older people (if you have done so), and planning for your own older years. The survey is expected to take about 10-15 minutes to complete and once completed can be posted to the researcher in the enclosed self-addressed and stamped envelope.

What are the benefits?  
Providing information on the questionnaire will contribute to the knowledge required by planners of future healthcare, housing and support needs for older people in New Zealand.

What are the potential risks and discomforts?  
There are no anticipated risks to you in participating in this study, but should any concerns regarding ageing and support needs arise for you, it is recommended that you discuss these concerns with your doctor, nurse, family support network or contact the office of the National Health and Disability Services Consumer Advocate (contact details below).
Confidentiality and data storage
Your name was selected randomly from the telephone directory however there are no means of identifying you on the questionnaire thus the information you provide will not be identifiable to you (please do not include your name or address). Data gathered from the survey will be held securely in the researcher’s office at the School of Nursing, University of Auckland, during the course of the study and for ten years following completion. Access to the information will be restricted to the researcher and research supervisors. Participants and their families will not be identified in any written reports associated with this research.

Withdrawal from the study
You can withdraw from the study at any time by not completing the questionnaire. Completion of the questionnaire is regarded as consent to participate. Withdrawal of information will be not be possible once the survey has been returned as there is no means of identifying you on the completed questionnaire.

If you have any questions or concerns about your rights as a participant in this research study you can contact the Regional (Northern X) Ethics Committee on 09 580 9105
If you wish to discuss issues for ageing, please contact Age Concern New Zealand. Local contact details for Age Concern can be found in the White Pages of the telephone directory. Or you could contact the Health and Disability Advocacy Service on 0800- 2787 7678, or by emailing advocacy@hdc.org.nz.

For further information please contact any of the following people:

| Principal Researcher: Helen Malcolm, Lecturer and PhD Candidate Tel: [09] 3737599 extn. 87934 h.malcolm@auckland.ac.nz School of Nursing The University of Auckland Private Bag 92019, Auckland | Research Supervisor: Associate Prof Dr. Robyn Dixon Tel: 09 3737599 extn. 87388 Director of the Centre for Child & Family Research, School of Nursing, University of Auckland, Private Bag 92019, Auckland | Head of Department: Associate Prof Judy Kilpatrick Tel: 09 3737599 extn. 87563 j.kilpatrick@auckland.ac.nz School of Nursing The University of Auckland Private Bag 92019, Auckland |

This study has received ethical approval from the Northern Regional Ethics Committee, ethics reference number NTX/10/EXP/074.

Thank you for considering participating in this survey.
11 May 2010

Ms Helen Malcolm  
c/- School of Nursing  
Faculty of Medical and Health Sciences  
The University of Auckland  
Private Bag 92019, Auckland 1142

Dear Helen

Ethics ref: NTX/10/EXP/074  
Study title: Perceptions and expectations of today’s adults regarding their ageing and future support  
Investigators: Ms Helen Malcolm  
Supervisor: Dr Robyn Dixon  
Localities: University of Auckland

Thank you for your application received 3 May 2010. The above study has been given ethical approval by the Deputy Chairperson of the Northern X Regional Ethics Committee under delegated authority.

Approved Documents  
- Protocol (dated August 2008)  
- Information Sheet (undated) – please insert footer with version number and date and forward an updated committee to us.

Accreditation  
The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

Progress Reports  
The study is approved until 1 August 2011. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator’s responsibility to forward a progress report covering all sites prior to ethical review of the project on 11 May 2011. The report form is available at http://www.ethicscommittees.health.govt.nz. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

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

Please quote the above ethics committee reference number in all correspondence.
It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

We wish you well with your study

Yours sincerely

[Signature]

Cheh Chua(Ms)
Assistant Administrator
Northern X Regional Ethics Committee
Are you aged between 40 and 65 years of age and interested in participating in an anonymous postal survey?

If so, you are invited to take part in a mail survey to find out about experiences of supporting older relatives or friends (if you have done so), and how you are planning for your own future ageing. Participation is voluntary.

**What is the purpose of the study?**

Although there is considerable research on the impact of ageing and implications for other family members, little is known about how the experience of caring for older relatives or friends influences people’s planning and expectations of their own ageing needs. Considering future needs and choice for support is important for the increasing population of older people in New Zealand.

**What is involved?**

The research involves completing a questionnaire which seeks the views of people between the age of 40 and 65 years. The questions cover a range of subjects related to your current lifestyle, observation and experience of caring for older people (if you have done so), and planning for your own older years. The questionnaire is expected to take about 10-15 minutes to complete.

The questionnaire is anonymous (no name included) so the information you provide in the survey will not be linked to you.

If you are interested in learning more please contact the researcher Helen Malcolm:

**Phone 923 7934 OR email h.malcolm@auckland.ac.nz**

If you want to participate please email you Name and Address to Helen and she will post you a copy of the information sheet, survey questionnaire and a free post envelope for return of the survey.

Thank you for considering participating in this survey.

This study has received ethical approval from the Northern X Regional Ethics Committee (Ref NTX/10/EXP/074)
References


References


References


232
References


References


References


van Maanen, H. M. Th. (2006). Being old does not always mean being sick: Perspectives on conditions of health as perceived by British and American elderly. *Journal of Advanced Nursing, 53*(1), 54-64. doi:10.1111/j.1365-2648.2006.03670.x


References


