

Ageing with Spinal Cord Injury in New Zealand

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Abstract

Background

Worldwide there is a new demographic phenomenon: an increasing number of people who either are born with or sustained a physical disability when young or in middle-age and who are now ageing with their disability. Spinal cord injury (SCI), whether sustained through injury or as a consequence of a medical condition, often results in life changing consequences. Previously, those with SCI had reduced life expectancy, and increased mortality and morbidity compared to their non-injured counterparts. However, in more recent times, the majority of people with SCI can, with appropriate care and support, expect to live an “almost normal” lifespan. Once regarded as a relatively stable condition, SCI is now recognised as being changeable over the life-course. This is the first study undertaken in New Zealand (NZ) specifically investigating people ageing with SCI.

Aim

The aim of the thesis has been to redress an information deficit and develop a better understanding of the health, living circumstances and quality of life (QOL) of people ageing with SCI in NZ.

Methodology

The research study used a mixed methods research approach using sequential methodology, with an exploratory qualitative phase (Phase 1) followed by the establishment of the SCI population in NZ (Phase 2) and a cross-sectional survey (Phase 3) of this population.

Phase 1 comprised a thematic analysis of in-depth interviews with 12 people who had lived with SCI for a minimum of 25 years. With the assistance of the two spinal units in NZ, Phase 2 established a database which included contact details of 1174 people who had incurred their SCI before January 1990. Potential participants were then invited to participate in Phase 3, a national cross-sectional survey.

Results

Phase 1 findings supported many of the conclusions from international research relating to ageing with SCI, yet provided additional insights into issues facing people who had lived with SCI for a prolonged period in NZ. All those interviewed had lived unique, full, active lives, often making major contributions to society. Specific issues identified included differences in funding between Ministry of Health and Accident Compensation Corporation (ACC), individual health status, living circumstances and QOL.

Surprisingly, during Phase 2, it became clear that the actual number of people ageing with SCI in NZ was unknown to health and other authorities, with many more people populating the database than anticipated. This raised questions about the effectiveness of health information systems and whether the needs of this group were underestimated and under-resourced.

Phase 3, which was comprised of a consenting sample of 284 people, provided a clear health and socio-demographic profile of people ageing with SCI incurred before 1 January 1990 in NZ. Establishing significant differences in the health and employment circumstances between participants who receive support from Ministry of Health and ACC was complex, with a number receiving funding for care and support from more than one source. Common health problems reported were high blood pressure or hypertension, arthritis or rheumatism, kidney or urinary tract conditions, hearing impairment, and bowel disorders. Participants maintained good social support networks and community involvement when compared to able-bodied people of a similar age. Time since injury was not significantly related to rated standard of living, satisfaction with standard of living, or income meeting current needs. Injury level was, however, ‘paradoxically’ significant with tetraplegics almost four times and paraplegics twice as likely to rate standard of living high or fairly high compared to people with SCI who were walking.

Conclusion

The research uncovered a ‘hidden population’ of people ageing with SCI, with many more people identified than anticipated by everyone involved. The need to construct the database, together with the technical issues associated with achieving this, reinforced the necessity for NZ to have a well-managed national SCI register. Most people ageing with SCI were living full, active lives, and contributing to the community. Many

participants, especially tetraplegics, rated standard and satisfaction of living, high, adding support for the ‘disability paradox’. NZ medical and social support services will need to respond to changing demographic trends with an increasing number of people ageing with SCI likely to present with a range of complex interwoven secondary conditions. People age whether they are disabled or not and experience health conditions that affect their life-course, making each individual’s life journey unique.

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distracted and at times grumpy. They are no doubt as relieved as I am that this project has actually finally come to an end.

Preface

I am a tetraplegic; a result of a rugby injury sustained in 1974 when I was aged 15 years. Since around 1995, some 21 years after my initial injury, I started to develop significant secondary complications, including shoulder problems and issues relating to my original neck injury. In 2002 I received neurosurgery which stabilised these complications. Around this time I started reading about people ageing with spinal cord injury and the emergence of hitherto uncharted secondary conditions that were being experienced. I realised that this was a rapidly evolving topic without much of an evidence-base; something desperately needed by people with spinal cord injuries, their families, care-givers, and clinicians. This led me to begin the journey of undertaking a doctoral thesis to investigate the topic further, especially in regard to what was happening to people ageing with spinal cord injury in New Zealand. It has been a personal journey of discovery and, at times, a sobering reality check as I have learnt a considerable amount about my own spinal cord injury and the ageing process. The thesis has been undertaken part-time over seven years. Over that time the research project was put on hold at times due to further health complications requiring additional neurosurgery in 2008, a family member being unwell in 2010, the unprecedented sequence of Canterbury earthquakes in 2010-11, and the subsequent 11,000 after-shocks. The building that my university department was based in was uninhabitable after the September 2010 earthquake. From that point on I worked from home to complete the thesis which, at times, has been difficult and stressful – not only for me but also for my wife and family. I am truly indebted to them for their continuous wonderful support throughout this research project.

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Table of Contents

Abstract.....	ii
Acknowledgements.....	v
Preface	vii
Conference presentations arising from this thesis	viii
Table of Contents.....	ix
List of Tables	xiv
List of Figures	xvi
List of Abbreviations	xvii
Chapter 1: Introduction.....	1
1.1 Introduction.....	1
1.2 Ageing internationally and in New Zealand	2
1.3 Disability internationally and in New Zealand	4
1.4 A new phenomenon: the ageing of people with disabilities	7
1.4.1 The implications of people with disabilities ageing	7
1.4.2 Brief overview of key ageing theories	8
1.4.3 Brief overview of key disability theories.....	11
1.4.4 The confluence and disjunction of disability and ageing	13
1.5 Rationale for the Study	15
1.5.1 Aims and objectives.....	15
1.6 Thesis structure	15
Chapter 2: Key policy and political developments in disability and ageing in New Zealand.....	18
2.1 Introduction.....	18
2.2 Political activism: finding a common voice	18

2.2.1 Disabled People	18
2.2.2 Older people.....	21
2.3 Key legislation and policies from 1970 onwards.....	25
2.3.1 Disabled people.....	25
2.3.2 Older people.....	29
2.4 Conclusions.....	34
Chapter 3: Literature review: Ageing with spinal cord injury	36
3.1 Introduction.....	36
3.2 Spinal Cord Injury	37
3.3 Life Expectancy, Mortality and Morbidity	41
3.4 Premature Ageing	43
3.5 Physical changes and deterioration associated with ageing with a SCI	45
3.6 Quality of life and psychosocial well-being	51
3.7 Environmental and community factors.....	63
3.8 Conclusions.....	66
Chapter 4: Methodology and overview of methods.....	70
4.1 Introduction.....	70
4.2 Mixed Methods Approach	70
4.3 Qualitative Research Approach	73
4.4 Quantitative Research Approach	74
4.5 Design of the Present Study	75
4.6 Brief overview of methods	78
4.7 Conclusion	79
Chapter 5: Phase 1 - Exploratory interviews with twelve people ageing with spinal cord injury.....	80
5.1 Introduction.....	80

5.2	Methods	80
5.2.1	Study design of Phase 1	80
5.2.2	Participants.....	80
5.2.3	Procedure	80
5.3	Results.....	86
5.3.1	The participants.....	86
5.3.2	Theme 1: Impact of SCI in the first few years.....	87
5.3.3	Theme 2: Living a long time with SCI	90
5.3.4	Theme 3: Specific issues associated with getting older.....	100
5.3.5	Theme 4: Living with SCI	107
5.3.6	Theme 5: Key issues likely to be encountered in the future	108
5.3.7	Theme 6: Things that could have helped in the past.....	109
5.3.8	Theme 7: The impact of technology and changes in medical knowledge and treatment	110
5.3.9	Theme 8: How a person's own experiences and knowledge had helped themselves and others	112
5.3.10	Theme 9: Impact of a person's cultural background	114
5.4	Conclusions.....	115
Chapter 6:	Phase 2 - Development of the research database	119
6.1	Introduction.....	119
6.2	Methods	119
6.3	Ethics	121
6.4	Subject Criteria	122
6.5	Setting and Process	122
6.6	Results.....	125
6.7	Conclusions.....	126

Chapter 7: Phase 3 - National cross-sectional survey of people with long-term spinal cord injury.....	128
7.1 Introduction.....	128
7.2 Methods	129
7.2.1 Study Design.....	129
7.2.2 Population	129
7.2.3 Questionnaire	129
7.2.4 Piloting the questionnaire	134
7.2.5 Procedure	135
7.3 Results.....	139
7.3.1 Participant recruitment.....	139
7.3.2 Participant profile	141
7.3.3 Living status of participants.....	152
7.3.4 Reported participant health, social interaction and health service use	162
7.4 Conclusions.....	179
Chapter 8: Discussion	185
8.1 Introduction.....	185
8.2 Reflections on the research	186
8.3 Issues relating to ACC and the Ministry of Health and/or Ministry of Social Development.....	190
8.4 Quality of life.....	193
8.5 The life-course and diversity of ageing with SCI.....	196
8.6 The future.....	199
8.7 Limitations of research	201
8.8 Recommendations.....	203
8.9 Conclusion	206
Glossary	208

Bibliography	210
Appendices.....	224

List of Tables

Table 3.1	Key quality of life studies involving people ageing with SCI.....	54
Table 5.1	Transcription principles used in reporting of thematic analysis	86
Table 7.1	Summary of the questionnaire's section headings, measures used and question source	133
Table 7.2	Demographic profile of participants (n=284)	142
Table 7.3	Injury characteristics of participants (n=284).....	144
Table 7.4	Educational qualifications of participants.....	145
Table 7.5	Participant occupations compared with the HWR sample and 2006 Census	146
Table 7.6	Current employment situation of participants compared to their preferred situation	147
Table 7.7	Sources of income and the type of superannuation scheme participants were enrolled in	148
Table 7.8	Reported participant income compared to HWR and 2006 Census income data	149
Table 7.9	Household living circumstances of participants	150
Table 7.10	Organising the provision of home help and attendant care (n=247).....	151
Table 7.11	Comparison of key demographic variables between participants (n=284) and non-participants (n= 614).....	152
Table 7.12	Participant injury level compared with selected characteristics (n=282)	153
Table 7.13	Relationship of participant rated standard of living to selected participant characteristics	155
Table 7.16	Correlation between variables rating standard of living, satisfaction with standard of living and needs being met by current income	160

Table 7.17	Odds ratio analysis of participant rated standard of living (high and fairly high) with participant characteristics	161
Table 7.18	Odds ratio analysis of participant rated income meeting everyday needs (more than enough and enough) with participant characteristics	162
Table 7.19	Reported SF-36v2 scores: SCI mean scores compared to HWR mean scores	163
Table 7.20	SF-36v2 mean physical and mental component summary scores compared with independent variables.....	165
Table 7.21	Participants reporting that a doctor, nurse or other health care worker had told them they have one or more health problem	168
Table 7.22	Reported alcohol consumption using the AUDIT Scale.....	169
Table 7.23	Reported smoking trends among participants.....	169
Table 7.24	Reported physical activity	171
Table 7.25	Reported provision of support and care for others	172
Table 7.26	Reported communication with family and whānau	174
Table 7.27	Interacting and communicating with other people	176
Table 7.28	Descriptive statistics of SCI and HWR populations on each subscale of the social provisions measure of perceived social support, together with a comparison of their mean differences.....	177
Table 7.29	Reported community health service use over the previous 12 months.	178
Table 7.30	Reported General Practitioner usage over the previous 12 months.....	178
Table 7.31	Reported hospital admissions over the previous 12 months.....	179

List of Figures

Figure 3.1	Diagram of spinal cord	39
Figure 3.2	Age at onset of SCI.....	44
Figure 4.1	Mixed-methods design matrix with mixed-methods design shown in the four cells. 73	
Figure 4.2	Adapted from Cresswell's Mixed Methods Sequential Exploratory Design (Cresswell, 2009 p. 209).....	76
Figure 4.3	Overall mixed methods study design adopted for this doctoral research	77
Figure 5.1	Process undertaken with interview participants.....	84
Figure 6.1	Admission boundary areas between the Auckland Spinal Rehabilitation Unit and Burwood Spinal Unit	120
Figure 6.2	Developing two databases of people with a SCI before 1 January 1990 based on admission to either the Auckland Spinal Rehabilitation Unit or Burwood Spinal Unit 124	
Figure 7.1	Participant flow diagram for Phase 3	139
Figure 7.2	Financial support for care and equipment.....	150
Figure 7.3	How participants rated their standard of living	154
Figure 7.4	Participant rated satisfaction with standard of living.....	156
Figure 7.5	Participants rating whether income meets every day needs	158
Figure 7.6	Scatterplot of participant's SF36v2 mental component score over (i) age (years) and (ii) years since injury, together with a superimposed lowess curve (a non-parametric mean estimator function)	166
Figure 7.7	Scatterplot of participant's SF36v2 physical component score over (i) age (years) and (ii) years since injury, together with a superimposed lowess curve (a non-parametric mean estimator function).....	166

List of Abbreviations

AARP	American Association of Retired People
ADL	Activities of daily living
ACC	Accident Compensation Corporation
ARA	Alliance of Retired Americans
ASRU	Auckland Spinal Rehabilitation Unit
AUDIT	Alcohol Use Disorders Identification Test
AUDIT-C	Alcohol Use Disorders Identification Test - short version
BPI	Brief Pain Inventory
BSU	Burwood Spinal Unit
CDHB	Canterbury District Health Board
CEO	Chief Executive Officer
CES-D	Center for Epidemiological Studies Depression Scale
CHART	Craig Handicap Assessment & Reporting Technique
CHD	Coronary Heart Disease
CHIEF	Craig Hospital Inventory of Environmental Factors
CMDHB	Counties Manukau District Health Board
CPI	Consumer Price Index
CPQ	Current Problem Questionnaire
CRPD	Convention on the Rights of Persons with Disabilities
DHB	District Health Board
DPCWA	Disabled Persons Community Welfare Act
DPA	Disabled Persons Assembly
DPI	Disabled Persons International
DSS	Disability Support Services

DSW	Department of Social Welfare
ERC	Earnings Related Compensation
FACIT-SP	Functional Assessment of Chronic Illness Therapies - Spiritual
FES	Functional Electrical Stimulation
FIM	Functional Independence Measure
GDP	Gross Domestic Product
GP	General Practitioner
HDL	High Density Lipoprotein
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
HRQOL	Health related quality of life
HSAUS	Health Services Access Utilization and Satisfaction
HWR	Health Work and Retirement Study
ICF	International Classification of Functioning, Disability and Health
ISEL	Interpersonal Support Evaluation List
IPWB	Index of Psychological Well-being
IYDP	International Year of the Disabled Persons
IYOP	International Year of Older People
LSI	Life Satisfaction Index
LSQ	Life Satisfaction Questionnaire
MCS	Mental Component Summary
MEC	Multi-regional Ethics Committee
MHCSQ	Medical History and Current Status Questionnaire
MoH	Ministry of Health
MSCIS	Model Spinal Cord Injury System
MSD	Ministry of Social Development

MVA	Motor vehicle accident
NHI	National Health Index
NZ	New Zealand
NZCD	NZ Council of Disabled
NSCID	National Spinal Cord Injury Database
NZDS	New Zealand Disability Strategy
NZST	New Zealand Spinal Trust
ODI	Office for Disability Issues
OECD	Organization for Economic Co-operation and Development
PACQ	Personal Attendant Care Questionnaire
PAS	Positive Ageing Strategy
PCS	Physical Component Summary
PSS	Perceived Life Scale
PIMS	Patient Information Management System
QOL	Quality of life
RINZ	Rehabilitation International NZ
RI	Rehabilitation International
RHA	Regional Health Authority
SAS	Sleep Apnoea Syndrome
SD	Standard Deviation
SCI	Spinal cord injury and/or condition
SOC	Selection, Optimisation and Compensation
SPS	Social Provision Scale
SWLS	Satisfaction With Life Scale
TASC	The Association of Spinal Concerns
UN	United Nations

USA	United States of America
VA	Veterans Association
WHO	World Health Organization
WHOQOL-BREF	World Health Organization Quality of Life short version
YPI	Years post injury
95% CI	95% confidence level

Chapter 1: Introduction

1.1 Introduction

There is a new demographic phenomenon occurring throughout the world: an increasing number of people who were either born with or sustained a physical disability when young or middle-aged are now ageing with their disability. These people are in many ways distinct from people who acquire a physical disability for the first time in old age. Biological deterioration is part of the ageing process and happens to all people regardless of whether they have a disability or are able-bodied people and is best understood in the context of an individual's life-course (Jeppsson Grassman & Whitaker, 2013). Following this reasoning it can be assumed that people with SCI (and disabled people generally) share specific experiences yet also have a wide range of different experiences and complications that will influence an individual's life-course as they age.

Spinal cord injury (SCI) mainly occurs among young and middle aged people after sustaining an injury or medical condition and is a disability that often has life-long major changing consequences. According to Derrett et al. (2012), there are approximately 100 to 120 people who sustain SCI in New Zealand each year, resulting in an estimated incidence rate of 30 per million. Life expectancy, mortality and morbidity have changed dramatically for the majority of people with SCI, who can expect with appropriate care and support to live an "almost normal" lifespan (Capoor & Stein, 2005; Kemp et al., 2004). Once SCI was regarded as a relatively stable condition, but it is now recognised as being dynamic and changeable over time. People living and ageing with SCI seem to have a period of relative stability post injury before developing a variety of physical secondary conditions (e.g. shoulder pain, stenosis, musculoskeletal deterioration) which can seriously compromise a person's lifestyle and even be life threatening (McColl et al., 2003). It is largely recognised and accepted in the literature that people with SCI age in ways that differ from their able-bodied counterparts. Secondary conditions and the associated medical complications that can develop seem to be related to the age the person had their initial injury and/or the length of time they have lived with their SCI. Overall, the majority of people ageing with SCI have long, positive and satisfying lives with many making major contributions to society.

People ageing with SCI are part of an increasing number of people ageing with a disability who are consumers of disability related services and with time are becoming consumers of age-related services along with those people who are ageing and incur a disability. Both groups of people may end up with similar physical functioning requiring similar care but have taken vastly different life pathways to get there. Such life-course diversity of people ageing is becoming increasingly recognised amongst researchers and gerontologists (Jeppsson Grassman & Whitaker, 2013; Molton & Jensen, 2010; Priestley, 2003; Putnam, 2002).

This is the first study undertaken in New Zealand specifically investigating people ageing with SCI. The project has been an exploratory journey, initially interviewing a group of people who had lived with long-term SCI, and then undertaking the first nationwide project specifically developed to explore the circumstances of people ageing with SCI. The number of people ageing with SCI and the circumstances they were living in were unknown. The aim of this thesis is to redress this information deficit and develop a better understanding of the health, living circumstances and quality of life (QOL) of people ageing with SCI in New Zealand. In order to understand the context for this research, this introductory chapter will explore international and New Zealand trends and theories in ageing and disability. There is a brief overview of recent theories associated with ageing and with disability to explore any common themes which may help explain the relatively new phenomenon of ageing with a disability. The implications of ageing with a disability are discussed, both for individuals, and in the context of population ageing. SCI internationally and in New Zealand is discussed, along with the specific aims and objectives of the current research and its methodological rationale.

1.2 Ageing internationally and in New Zealand

Population ageing is a global phenomenon without parallel in human history, with there now being more older people than children; and more people in extreme old age than ever before (World Health Organization, 2011a).

Worldwide

The number of people aged 65 years or older is projected to grow from an estimated 524 million in 2010 (8% of the world's population) to nearly 1.5 billion by 2050 (16% of the world's population), with most of the increase taking place in developing countries. Between 2010 and 2050 the number of older people in the least developed countries is projected to increase more than 250% compared to 71% in developed countries, driven by declining

fertility and improvements in longevity (World Health Organization, 2011a). At the beginning of the 20th century the major health threats were infectious and parasitic diseases, most often affecting infants and children. Now non-communicable diseases, which mainly affect adults and older people, place the greatest burden on health systems internationally. In developing countries a rise in chronic non-communicable diseases such as heart disease, cancer and diabetes reflects changes in lifestyle and diet as well as ageing. The conditions that currently account for the bulk of mortality and morbidity among older people stem from experiences and behaviours at younger ages such as smoking, alcohol abuse, infectious disease, under- and over-nutrition, poverty, lack of access to education, dangerous work conditions, violence, poor health care, and injuries. For reasons not entirely clear, women in developed countries have a higher life expectancy than men, a pattern which is also emerging in developing countries (World Health Organization, 2003, 2011a, 2013c).

The rising life expectancy within the older population itself is associated with a rise in the number and proportion of people at very old ages. In 2010, people aged 85 years and over made up 8% of people aged 65 years and over (World Health Organization, 2011a). The use of health services by adults increases with age, with expenditure on health being relatively high in the older age groups. The rising proportion of older people will place increasing pressure on health care and social support service spending in the developed world. Also factors such as income growth and advances in the technological capabilities of medicine are generally playing a much larger role in keeping people alive much longer whereas previously they would most likely have died (Priestley, 2003; World Health Organization, 2011a).

New Zealand

Compared to other Organization for Economic Co-operation and Development (OECD) countries, New Zealand's population in the older age groups is projected to remain relatively low. This is largely due to New Zealand's fertility rates having remained higher than most other OECD countries (Statistics New Zealand, 2006). The median age of New Zealand population in 2012 was 37 years with half the population projected to be 41 years and older by the late 2030s. The number of people 65 years and older in New Zealand has doubled since 1980 to 600,000 in 2012, and is expected to double again by 2036 to approximately 1.18 to 1.25 million people. The proportion of New Zealanders aged 65 years and older is projected to rise from 14% in 2012 to approximately 25% by 2050. Based on life tables for 2005–07, a newborn girl can expect to live 82.2 years on average, and a newborn boy 78.0 years. Māori life expectancy is significantly lower than non-Māori, with females having a life expectancy

of 75.1 years and males a life expectancy of 70.4 years. Ethnic diversity is set to increase by 2026, with Māori comprising 16% of the total population (15% in 2006), Pacific people 10% (7% in 2006), and a broad Asian ethnic group making up 16% of the total population (10% in 2006). European and ‘others’ will continue to be the largest ethnic group, projected to comprise 70% of the total population in 2026 (77% in 2006). It is important to note that these populations are not mutually exclusive with people identifying with more than one ethnicity, and therefore can be counted in more than one ethnic population. In the Māori and Pacific populations the growth is mainly driven by higher fertility rates combined with a youthful age structure, whereas the growth of the Asian population is mainly driven by net migration gains. It is anticipated that there will be major implications for health and social welfare expenditures with significant increases required to cover the rise in the incidence of disability with age and increased need for health treatment and care, as well as social services (Statistics New Zealand, 2006, 2013).

1.3 Disability internationally and in New Zealand

The United Nations *Convention on the Rights of Persons with Disabilities* (CRPD), adopted in 2006, aims to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”. The *International Classification of Functioning, Disability and Health* (ICF), defines disability as an umbrella term for impairments, activity limitations, and participation restrictions. Disability refers to the negative aspects of the interaction between individuals with a health condition (such as physical injuries, cerebral palsy, Down syndrome, depression) and personal and environmental factors (such as negative attitudes, inaccessible transportation and public buildings, and limited social supports) (World Health Organization, 2011b).

Worldwide

Based on 2010 global population estimates, there are more than 1 billion people living with some form of disability (about 15% of the world population). The number of people with disabilities is growing because populations are ageing. Older people have a higher risk of disability, and so there is now a global increase in chronic health conditions associated with disability such as diabetes, cardiovascular diseases, and mental illnesses. Chronic diseases are estimated to account for 66.5% of all years lived with a disability in low income and middle income countries (World Health Organization, 2011b). Disability trends vary across countries

and are influenced by health conditions and environmental factors which include natural disasters, conflict, diet and substance abuse. Disability disproportionately affects vulnerable populations resulting in higher disability prevalence in lower income countries compared with higher income countries. People with disabilities experience poorer levels of health than the general population and have a greater vulnerability to developing preventable secondary conditions, co-morbidities and age-related conditions. There is also a higher risk of being exposed to violence, and experiencing higher rates of poverty than non-disabled people. A lack of rehabilitative services and assistive devices (wheelchairs, prosthetic devices etc.) can result in deterioration in general health status, limitations in activity and participation, and a reduced QOL. Children with disabilities are less likely to start school than their peers without disabilities, and have lower rates of staying and being promoted in school.

People with disabilities are less likely to be employed and, once employed, generally earn less. Global data from the World Health Survey shows that employment rates were 53% for disabled men compared to 65% for non-disabled, and 20% for disabled woman compared to 30% for non-disabled women (World Health Organization, 2011b). A study by the OECD showed that in 27 countries working age people with a disability had an employment rate of 44% compared to 75% for people without a disability (OCED, 2010). It is recognised that disabled people often lack autonomy and are segregated from the wider community. Most support comes from family members or social networks which can cause caregivers stress, isolation and loss of socioeconomic opportunities (OCED, 2010; World Health Organization, 2011b).

In relation to SCI it is estimated that between 250,000 and 500,000 people globally sustain a SCI every year. The majority of SCI are due to road traffic accidents, falls or violence. A person with SCI are two to five times more likely to die prematurely than people without SCI. Mortality risk increases with the severity of injury level, and is strongly influenced by the availability of timely and quality medical care. Secondary conditions (e.g. urinary tract infections, pressure ulcers) are no longer among the leading causes of death of people with SCI in high-income countries, but these conditions remain the main cause of death in lower-income countries (World Health Organization, 2013b). The incidence rate and age at injury varies considerably between countries, with differences in social and political environments as well as methodological differences between reviewed studies making accurate comparisons challenging. Reported incidence of SCI varies between 10.4 and 83 per million. One third of those with SCI are tetraplegics, with 50% having a complete lesion. Approximately 80% of

those people who sustain SCI are male. Motor vehicle accidents (MVAs) in the 15 to 44 years age group consistently appears to be the most common cause of SCI, followed by falls in the over 60 years age group. With the number of falls in the older age groups increasing, van den Berg et al. (2010) suggest that prevention of SCI should not only focus on young males but also on older adults who show peak incidences mainly from falls. With the worldwide population aged over 65 years predicted to double over the next 40 to 50 years, it can be anticipated that there will also be an increase in incidence of non-traumatic SCI. This may have major implications for the organization and delivery of care and community services (Burt, 2004; Ho et al., 2007; Jackson et al., 2004; van den Berg et al., 2010; Wyndaele & Wyndaele, 2006).

New Zealand

In New Zealand the 2006 Disability Survey estimated that there were 660,300 people with a disability (17% of the total population). This is significantly lower than rates from the previous two surveys in 1996 and 2001, where it was reported that 20% of the population had a disability. Statistics New Zealand (2007) suggest the decline in the disability rate is likely to be due to a combination of factors relating to the way the 2006 survey was conducted, and people's changing perception of disability, as well as a possible genuine decrease. In 2006, 80% of disabled people were adults living in a household, 5% were adults living in residential facilities, and 14% were children aged 15 years and under living in households. The percentage of people with a disability increased with age, and 45% of adults aged 65 years and over had a disability. One third of people with a disability were in the 65 years and over age group. Males had a slightly higher rate of disability in age groups less than 65 years while females had a higher rate in the age group 65 years and over.

In the adult population 15 years and over, 12% (383,500) had a physical disability, 8% (239,000) a sensory disability (hearing and/or eyesight), and 7% (224,500) reported having other types of disability such as difficulty speaking, learning, remembering or doing everyday activities. Diseases or illnesses (7%) were the most common cause of disability for adults followed by accidents or injuries (5%), ageing (5%), other causes (5%), and disability existing at birth (2%). For people having an accident or injury causing a disability, this most commonly happened at work. It is important to note that people may have more than one type of disability. Forty percent of adults with a disability had a single disability and 60% had multiple disabilities. The percentage of people with multiple disabilities increased with age.

Sixty three percent of females and 54% of males with a disability reported having multiple disabilities.

In 2006 there were an estimated 96,600 Māori people with a disability in New Zealand (14.6% of all disabled people), with 99% living in households. They make up 17% of the total Māori population compared to 11% of Pacific peoples and 18% of European people. Māori and Pacific peoples have a different age structure from European, with 80% of Māori being aged less than 45 years, compared to 54% of the European population. The high proportion of young people in the Māori population results in 63% of disabled Māori being aged less than 45 years. The Pacific peoples were estimated at 24,800 (3.8% of all disabled people) with 98% living in households. Fifty-seven percent of Pacific peoples with a disability were aged less than 45 years. The most common causes of disability for Māori adults were disease or illness (34%) followed by accidents or injuries (32%). For Pacific adults, diseases and illnesses accounted for 43% of all disabled Pacific adults (Statistics New Zealand, 2007b).

With regard to SCI, Derrett et al. (2012) estimated the annual incidence of SCI (traumatic and non-traumatic) at 30 per million, based on two years of clinical data obtained from 230 people admitted to the two spinal units in New Zealand. Compared with those of European origin (29 per million), the incidence of SCI was high among Māori (46 per million), and higher still among Pacific people (72 per million). In an earlier study Dixon et al. (1993) found MVAs (54%) were the leading cause of SCI followed by falls (24%).

1.4 A new phenomenon: the ageing of people with disabilities

1.4.1 The implications of people with disabilities ageing

In the Western world people with disabilities and aged people have been two separate groups, each who have actively pursued their own political agenda for improved recognition, equal rights and funding (see Chapter 2). The increasing number of young or middle-aged people living with a disability long enough to be considered as ageing with a disability creates a new cohort of aged people. These people are distinct from those who have acquired a physical disability for the first time in old age. There is a wide range of physical disabilities that can be acquired at birth, or when young or middle aged, including SCI, diabetes, arthritis, polio and multiple sclerosis and the consequences of stroke and cancer. With advances in medical treatment and care, and rehabilitation, these people are living near normal life expectancies. There is increasing evidence that people with physical disabilities tend to age differently than non-disabled people due to an array of secondary conditions that develop during their lifespan

or life-course (Adkins, 2004; Molton & Jensen, 2010). The development of secondary conditions such as heart disease, obesity, pain, fatigue, musculoskeletal issues and depression can have a negative influence on QOL, employment and community participation. The increasing number of people ageing with a disability and those people ageing who sustain a disability later in life may end up with very similar physical limitations and social circumstances that require similar care and support, however, they have taken vastly different life pathways to get there. This will result in an increasing number of people who are ageing with a disability and are consumers of disability related services also becoming, in time, consumers of age-related services (Daatland & Biggs, 2006; Jeppsson Grassman & Whitaker, 2013; Molton & Jensen, 2010; Priestley, 2003; Putnam, 2002).

1.4.2 Brief overview of key ageing theories

Theories on ageing cover many fields such as biology, psychology, anthropology, and sociology. Koopman-Boyden (1993) reviewed theories of ageing, asking core questions, such as whether ageing is regulated intrinsically or by environmental factors. It was suggested that environmental factors contribute to modifying mortality rates and even the process of ageing. However, Koopman-Boyden suggests that only when the relationship of the ageing process to social and environmental factors is established and understood will it be possible to do something about it.

Critical gerontology has attempted to answer such questions by examining both society and the field of gerontology itself. It questions and challenges areas such as biomedical research which ignores social and environmental factors; the normative construction of the life course; indifference to gender, race, class and age relations (Ray, 2008). It includes theories based in critical theory, the political economy of ageing and social phenomenology and feminist perspectives on ageing. The political economy of ageing explores how socially produced definitions of old age have impacted on both public policy and the structure of public and private organizations. The feminist perspective on ageing focuses on using factors such as age, race, class and gender to examine how power differentials within social structures influence the ageing process. Neither of these research traditions initially addressed ageing with a disability or having a disability in old age. In recent works there have been calls for the inclusion of disability as an independent factor. There is recognition that age itself is socially and culturally constructed and this view has clear parallels with the social model of disability discussed in more detail in section 1.4.3 (Holstein & Minkler, 2003; Moody, 2008; Ray, 2008). Within critical gerontology there has been an attempt to understand how demands from

environmental factors act as barriers or facilitators which impact on older people with physical impairments. The ecological model of ageing theory discusses where the balance of optimal functioning occurs between environmental demands and individual capabilities. A change, such as increased environmental pressure or reduced individual competency, results in the need to rebalance the equation by modifying either the person or the environment to deal with a new scenario. For example a person requiring a wheelchair would need to change his or her environment to suit the wheelchair. An addition has been proposed to the ecological model of ageing that emphasises the need to maintain a person-environmental fit to achieve psychological well-being. Putman (2002) concluded that there is a good set of theories to explain the general phenomenon of ageing; however, they have not necessarily been designed to accommodate the concept of people ageing with a physical impairment. Oldman (2002) also suggested the social model of disability fits well with a post-modern view of later life and reinforces self-identity and confronts the myths of independent living.

In the late 20th century, three major theories of individual ageing are the disengagement theory, activity theory, and continuity theory (Putnam, 2002). Disengagement theory proposes a natural disengagement from life roles as the way to greater life satisfaction for older adults. Activity theory proposes that the maintenance of activity is crucial for high levels of life satisfaction in old age. Continuity theory proposes that individuals preserve both internal psychological and external structure in the social and physical environment by making adaptive choices that allow them to feel a sense of continuity between past and current events, enabling them to maintain a stable yet evolving sense of self as they age. None of these theories includes a framework for people ageing with physical impairment or recognise the concept of younger people ageing with a disability.

Additional theories about the relationship between individuals and society include the social exchange, modernisation, and the age stratification theories which all focus on the structure of society and the roles available to older adults. The social exchange theory suggested by Dowd (1975) examines the cost-benefit relationship between the individual and society where it is suggested as a person ages the cost-benefit ratio falls out of balance and the costs associated with interacting with an older person often outweigh the benefits. The modernisation theory developed by Burgess in 1960 proposes that the emergence of new technology effectively makes an older person lose their place of prestige and power within society as they age and cannot compete in the changing marketplace, therefore they become marginalised (Putnam, 2002). It is suggested that older people need to up-skill and retrain as they age. The age

stratification theory developed by Riley et al. (1972) suggests that society expects the social roles of an individual to change over that person's life course based on their age. Therefore a person may go through a variety of transitional roles throughout their life course as they age. There is an acknowledgement that a change in resources, including a decline in physical health, can upset the relationship between the individual and society.

None of these theories directly addresses the concept of how living with a long-term disability alters the individual's position within society. With the exchange and modernisation theories there is an emphasis on the reduction of an individual's marketplace value. The age stratification theory suggests a variation in ageing within and between birth cohorts on the basis of health status as well as gender, ethnicity and class.

To understand how people successfully master the challenges of ageing Baltes and Carstensen (1996) proposed a model that describes three strategies of adaptively, responding to everyday demands and functional decline later in life - Selection, Optimisation, and Compensation (SOC). Selection is defined as actively or passively reducing the number of activities, goals, or domains in order to focus on those areas that are the most important in one's everyday life. Optimisation is defined as the enhancement and refinement of the means to maximise resources in a selected domain of functioning. This includes adaptive processes or strategies where no direct or indirect ageing losses have occurred. Society can play a key role in providing environments that facilitate optimisation. Compensation refers to the use of new or alternative means to reach a goal, or maintain a desired state, once losses have occurred. It is suggested that when adapting to ageing losses, compensation is more likely to occur when alternative means or resources relevant to the achievement of the same goal are available (e.g. using a hearing aid). Older people rich in resources tend to be more capable of compensating when confronted with losses rather than older people who have poor resources (Baltes & Carstensen, 1996; Lang et al., 2002). This theory recognises that individuals make choices as they age which influence their QOL.

Molton and Jensen (2010) suggest that the most dominant contemporary theoretical model of ageing is the lifespan developmental approach in which development occurs throughout a person's lifespan, and not just during the years of childhood and adolescence. Individuals make continuous adaptations to changing external demands. This theory incorporates the concept of 'ageing differently' or 'differential ageing' whereby people may change on many dimensions simultaneously and there may be multiple forms of functional change within a person. The lifespan development theory emphasises the interaction of biological, social and

psychological factors and takes into account the impact of shared experiences created at a particular point in time for a group or cohort of people.

Central to the lifespan developmental model are both Baltes' original concept of 'successful ageing' with its SOC model and the notion of on-time/off-time events. On-time/off-time events refer to the sequence of experienced life events that would normally be expected or are unexpected during a person's lifespan. A person can be seen to have aged successfully when they continue to perform life tasks that are personally meaningful and important despite any decline in skills, memory and performance. Although the model has been developed to explain normally ageing individuals, including those ageing into disability, it has rarely been applied to adults ageing with a disability (Molton & Jensen, 2010). However, it seems to work well when applied to this scenario. For example, if a person has a SCI in their late teens, it would be regarded as an off-time event in the lifespan of a person. Successful ageing occurs when an individual is able to compensate for losses in function and actively selects activities that are within his or her abilities, and actively seeks behaviours that enrich QOL.

Molton and Jensen (2010) suggest that a major model, the socio-emotional selectivity theory which is designed to account for age-related changes in social support, coping and engagement, covers the same processes present in younger and middle aged adults facing chronic disease or disabilities. It suggests that increasing age and perceived limited time left to live leads people to reprioritise and reorganise their goals to achieve an improved future. Those people who perceive a long life ahead of them will have different goals from those older people who perceive they have little time left. It is suggested that older people focus more on emotionally gratifying interactions and other pursuits which bring benefits immediately. Molton and Jensen (2010) suggest that in socio-emotional selectivity theory it is the time perspective rather than actual chronological age that this drives the reorganization of goals. For example, a person with long term disability, ageing with secondary symptoms (such as fatigue, pain, and weakness) and a greater rate of decline in independence may begin to prioritise emotion-focused strategies more than problem-focused strategies, and focus on emotionally gratifying interactions with social partners and other pursuits whose benefits can be realised in the present, rather than in the uncertain and shifting future.

1.4.3 Brief overview of key disability theories

The social models of disability are based on the concept that the disability is not part of the person, but rather a function of the interaction between the person and the environment.

Disability is a consequence of the capabilities of the individual and the demands of the environment. Therefore the individual may have a physical disability but, on its own, this does not constitute a disability. With social models of disability there is a close link between the theories and active political action as a background theme to gain an understanding of disablement that supports arguments for social change. Oliver (2013, p. 1) reflectively comments on the development of the social model:

It soon became the vehicle for developing a collective disability consciousness and helped to develop and strengthen the disabled people's movement. Armed with the idea that we needed to identify and eradicate the disabling barriers we had in common, that disabled people's movement forced the media to change their image of us, transport providers to open up many of the services to us, public buildings to become much more accessible and the legal system changed to make it illegal to discriminate against us.

There are multiple social models of disability such as the functional limitation models, disability process models, and the political framework models. The functional limitation models identify limitations or impairments that affect the individual's ability to perform the tasks and obligations of his or her usual roles in normal daily activities. A disability limits performance of socially defined roles and tasks within a socio-cultural and physical environment that is related, but not equivalent, to the disability and functional limitation. The disability process models added the concept of risk factors (that may include demographic, social, lifestyle, behavioural, psychological, environmental, and biological factors as predisposing characteristics) and QOL. The enabling-disabling process model describes the interaction between the person and the environment as a context of disability. Determination of the disability is dependent on the particular environment within which the individual is functioning. Disability is not located within the individual but rather is created by a situation where the physical capabilities of the individual and the demands of the physical or social environment are not in alignment. The minority group model of disability considers social attitudes to be the root cause of disability, leading to stigma and discrimination. Changing political policies as well as characteristics of the social and physical environment would alleviate disability (Bickenbach et al., 1999; Oliver, 1990, 2013; Putnam, 2002; Shakespeare & Watson, 1997).

1.4.4 The confluence and disjunction of disability and ageing

Earlier theories on ageing did not consider the concept of sustaining a disability when young or middle aged and living with that disability into old age. Putman (2002) suggested that by incorporating disability and physical impairment as factors into many of the existing ageing theories will advance their conceptual ability to examine ageing with disability. This is reinforced by the concepts pursued by contemporary critical gerontology. The relatively recent ‘critical turn’ includes the more recent theories on ageing such as critical social theory, lifespan developmental theory, socio-emotional selectivity theory and life-course theory which seem to be able to incorporate the concept of younger and middle aged people with a disability ageing to a stage in life where they can be considered aged with a disability (Jeppsson Grassman & Whitaker, 2013; Molton & Jensen, 2010; Putnam, 2002). Regarding various social models of disability, Putman (2002) suggested that they provide a framework to explore the experience of ageing with a physical impairment within the person-environment relationship. People with a disability and the environment both have adaptive capabilities to create a more balanced situation. The social models of disability are fundamental building blocks of the philosophies of self-determination and independent living that are the core of many disability service models that could equally be applied and used for older people ageing positively and independently (Oldman, 2002; Priestley, 2003; Putnam, 2002). How disabled and older age groups historically pursued separate political agendas when lobbying for change in societal attitudes and government policies, not recognising at the time that there was and is much in common between the two groups, will be explored in more depth within the literature review (Chapter 2).

Priestley (2003) suggested that there are two important and intersecting trends. The first include medical, technological and social developments that have ensured a dramatic increase in the number of younger disabled adults surviving into old age, raising questions about the ways in which societies respond to disability issues amongst ageing populations. The second is the general trend of population ageing which means that the number of previously non-disabled adults who acquire impairments in later life is also increasing. These trends suggest that there may be a convergence of disability status and experiences in later life between older people who grew up with impairments and those who acquired them when older.

Lowton (2013) talks about a ‘new’ ageing population of people born with serious health conditions who are now reaching adult life due to advances in preventative and curative medicine, and changes in social attitudes and health interventions. Lowton adds that these

people will challenge the boundaries of old age by extending issues usually associated with gerontology to wider groups of 'old' people, many of whom are pioneers with no cohort or tradition ahead of them. This change in the patterning and nature of 'old age' and health is becoming increasingly recognised as an important issue amongst policy-makers, researchers and health professionals. There are a growing number of people who acquired a disability when young or middle aged who are now on the brink of becoming older with a long-term disability. Oldman (2002) suggests there are strong parallels in the experiences shared between older and disabled people such as living with pain and limited impairment, discrimination and the need to cope with a medicalised health care system. There are major implications ahead for the health and social support services and funding for many countries throughout the world.

A large number of people ageing with a long term disability are currently consumers of disability related services and at some point due to their age they will become consumers of age-related services. It seems unclear how the development of this cohort of ageing people with long-term disabilities with their associated complex secondary conditions will impact on services for the older age groups. Biological deterioration is part of the ageing process and happens to all people regardless of whether they have a disability or are able-bodied. Jeppsson Grassman and Whitaker (2013, p. 4) suggest that the meaning of a person's disability is best understood in the context of the dynamics of the whole life-course and with an approach in which ageing is seen as a lifelong process. They add that this life-course approach contributes to illuminating the considerable variation in people's experiences over time, due to differences in individual resources and positions as well as there being shared experiences. Following this reasoning it can be assumed that people with SCI (and disabled people generally) share specific experiences yet also have a wide range of different experiences and complications that will impact on an individual's life-course.

By the mid-2040s there will be a dramatic increase in the number of people aged 65 years and over both worldwide and within New Zealand. Currently approximately 15% of the world population and 17% of the New Zealand population have a disability. The numbers of people with disabilities is growing as the population ages and faces a higher risk of chronic health conditions. Disabled people and older people, who, in the past, have been seen as separate groups, are both diversely ageing as people (with or without a disability) following their individual life-courses as they age. Such diversity includes differences in cultural, gender, health complications, religion and social backgrounds to name a few. Although there is

diversity, the two separate groups are also becoming more alike and converging as disabled people age to the point where they join those people who have incurred a disability when older. This will have major implications for Government policy making and funding in New Zealand as increasing numbers of people with disabilities currently funded by the disability related health and support services (Ministry of Health, ACC) come under the responsibility of age-related health and support services in increasing numbers.

1.5 Rationale for the Study

1.5.1 Aims and objectives

The aim of the current research study was to undertake exploratory research nationwide to gain better insight and understanding as to the living circumstances of people ageing with SCI in New Zealand and compare the findings with international research on ageing with SCI.

The study uses a mixed methods sequential exploratory approach with the findings of Phase 1 (the qualitative research project) assisting to develop Phase 3 (the quantitative research project). Phase 1 used a qualitative research approach with the in-depth interviews identifying key issues that had affected those interviewed as they aged with SCI. It was unknown how many people there were in New Zealand living with SCI, and no readily available contemporary reliable register existed. Therefore, with the assistance of the Auckland Spinal Rehabilitation Unit (ASRU) based in Auckland and the Burwood Spinal Unit (BSU) based in Christchurch, a research database was established that identified and captured a population of people who had incurred SCI before 1 January 1990 (Phase 2). The database information was retained by each spinal unit until the process to undertake Phase 3 a quantitative research study was developed. Phase 3 involved a cross-sectional national survey with the specific aims of determining the health, living circumstances and QOL of the population. The findings from the Phase 1 the qualitative research study and Phase 3 the quantitative research study were compared with international research on ageing with SCI, with similarities and differences being identified.

1.6 Thesis structure

Chapter 1 gave a brief overview of ageing and disability population trends worldwide and in New Zealand. A brief overview of the key theories regarding ageing and disability explored common themes which helped explain the relatively new phenomenon of ageing with a disability. The implications of ageing with a disability were discussed. The specific aims and

objectives of the current research were explained including the methodological rationale of the research phases undertaken.

Chapter 2 briefly discusses the implications of disabled people and older people becoming politically active, and the development of key issues and New Zealand Government policies and strategies such as the introduction of Accident Compensation Corporation (ACC), the New Zealand Disability Strategy (Ministry of Health, 2001) and the Positive Ageing Strategy (Office for Senior Citizens Ministry of Social Development, 2013).

Chapter 3 reports a focused literature review of research that has been undertaken on ageing with SCI, covering specific issues such as the medical complications associated with developing secondary conditions, QOL, and the impact of environmental influences.

Chapter 4 introduces the methodology used in the research. The chapter covers the rationale for undertaking a mixed methods exploratory sequential approach involving qualitative and quantitative research approaches. The chapter sets out the three phase study design for the research.

Chapter 5 documents Phase 1, which involved a qualitative research approach. Twelve in-depth interviews were undertaken with people who had lived with their SCI for a minimum of 25 years. The chapter reports on the common themes and issues which specifically related to living and ageing with a SCI over many years. The key issues identified were used to assist with the development of the questionnaire used in Phase 3.

Chapter 6 presents Phase 2, which involved developing separate databases from the ASRU and BSU, respectively, to create the final research database. Information obtained from the Ministry of Health's Patient Management Information System (PMIS) was reviewed to identify a population of people who had sustained a SCI before 1 January 1990 and were resident in New Zealand with contact details.

Chapter 7 documents the process and findings of Phase 3, a national cross-sectional survey of people ageing with SCI. The process outlines how the details of the people on the two databases established in Phase 2 had their health status and contact details rechecked and updated. Individuals were contacted by the two spinal units seeking consent to participate in the study. Participants were sent either an electronic survey questionnaire or a paper-based version via the post, to obtain baseline information about people ageing with SCI, such as general demographic and health-related QOL information and living circumstance information. Comparative analysis drew on information obtained from Massey University's

2006 study into Health Work and Retirement (HWR), an age appropriate New Zealand-based national sample, and information from the 2006 New Zealand Census and the Health of New Zealand Adults 2011/12 survey.

Chapter 8 discusses the key findings in the research undertaken, relating the findings to key issues that have been highlighted. Limitations of the study's research are discussed. Recommendations on future research, policy and health and support service needs are made, followed by concluding comments.

Chapter 2: Key policy and political developments in disability and ageing in New Zealand

2.1 Introduction

The previous chapter presented a general overview of ageing and disability and discussed how the relatively new phenomenon of people who sustained a disability when young or middle aged are now ageing with their disability, creating a new cohort of older people who will require specific health and social support services. This chapter summarises the important development of political activism from the 1970s onwards internationally and in New Zealand amongst disabled and older people which led to the creation of representative organizations that lobbied for particular political agendas. This increased political activity and recognition at Government level influenced the development of key New Zealand Government policies such as making it unlawful to discriminate against age and disability (*Human Rights Act 1993*), the New Zealand Disability Strategy, and the Positive Ageing Strategy.

2.2 Political activism: finding a common voice

2.2.1 Disabled People

The development of the disability rights campaign was a global movement, but in this instance the thesis will refer to how the rights of the disabled developed in the United States of America (USA) and New Zealand as selected examples. The disability rights campaign movement grew out of the civil rights movements in the USA during the 1960s. Naturally it was not just the USA which gave birth to the disability social movement but also Great Britain and other Western countries (Beatson, 2004). Peter Beatson (2004, p. 251) states the concepts that spread worldwide were the move from charity to rights, the demand for partnership or control in their own organizations, the development of pan-disabled consciousness, and internationalism. Beatson suggests that a common thread throughout the disability movement was a call for the charity model to be replaced by a rights-based one, whereby disabled people should not be reliant for their livelihood and participation on favours conferred by able-bodied society. As citizens of a national state people with disabilities have a right to education, jobs and welfare, to dignity, respect and autonomy as well as a right to be free from prejudice and discrimination. Throughout the 1970s there was growing

radicalisation of disability consciousness that led to a drive not just for rights and partnership but also autonomy and self-control. This climaxed in the 1980 Winnipeg walkout (or ‘wheel-out’) from Rehabilitation International (RI: a federation of rehabilitation agencies dominated by able-bodied service providers) by disabled participants in a protest against the able-bodied domination within the organization. The following year the Disabled Persons International (DPI) formed; a pan-disabled, global organization, run by and for the disabled themselves, and dedicated to the advancement of disability rights worldwide (Beatson 2004).

In New Zealand in the 1970s people with different disabilities started to communicate and cooperate with each other, which eventually led to the formation of the New Zealand Council for the Disabled. For the first time representatives of disabled people began meeting and talking on a national level. This peaked with the planning for the United Nations sponsored 1981 International Year of Disabled Persons (IYDP) which called for a plan of action emphasising equality of opportunities, rehabilitation and prevention of disabilities. This was followed by the formation of the Disabled Persons Assembly (DPA) in 1983, which grew out of three national bodies: the NZ Council for the Disabled (NZCD), Rehabilitation International New Zealand (RINZ), and the DPI. It was through negotiations, led by DPI, that the three organizations merged into one. The DPA now has approximately 300 organizational members and 1200 individual members. It has national headquarters in Wellington and small local branches in towns throughout the country, with considerable autonomy at branch level (Disabled Persons Assembly NZ, 2013). The formation of this single organization brought together representatives of Government, service agencies, and individual disabled consumers. A major achievement for the DPA was to successfully lobby for an amendment to the *Human Rights Act 1993* which made it illegal to discriminate ‘unreasonably’ against people on the grounds of disability.

The first major case regarding disability and the Human Rights Act was the Wellington-based Stagecoach bus company which bought a fleet of 80 inaccessible buses, preventing access for people using wheelchairs. It raised the issue of access for the disabled to public transport. After the Human Rights Review Tribunal reviews during 1995 and 1996, concessions were made by the bus company but it still did not allow access to those in wheelchairs due to the costs involved. It left unresolved the question of what was considered ‘reasonable’ for disabled people to expect by way of accommodating their needs and what was reasonable for public service providers to deny (Beatson, 2004; Disabled Persons Assembly NZ, 2013; Ministry of Justice, 2013).

People with SCI have actively been involved in the development of the disability organizations. Beatson (2004) notes that John Stott, a New Zealand paraplegic, was the first disabled person elected world president of RI in 1982. In this role he introduced a number of wide-ranging structural and financial reforms. John's international work continued after his retirement from the RI with him being an active member on the United Nations (UN) panel for the implementation of the Standard Rules for the Equalisation of Opportunities for Disabled Persons until his untimely death. Many other people with SCI have been actively involved in the development of DPA and organizations, such as the New Zealand Paraplegic and Physically Disabled Federation which was formed as a national sports organization for people with disabilities in 1968. It was later renamed PARAFED in the 1990s and then again in 1998 to Paralympics New Zealand – to gain greater public awareness and profile (Paralympics New Zealand, 2013).

Professor Alan Clarke, who was Dean of the University of Otago's Christchurch School of Medicine (now known as University of Otago Christchurch) from 1986 to 1994, sustained a SCI in 1991 resulting in paraplegia. In 1994 he became Director of the Burwood Spinal Unit (BSU) and established the New Zealand Spinal Trust (NZST) that same year (Abernethy, 2007). He experienced first-hand what it was like to have a SCI and be rehabilitated through a spinal unit under a medicalised system. He believed there was a better way for people with SCI to be rehabilitated and that was for the patient or 'client' to become responsible for his or her own care. At the time it was a revolutionary way of applying rehabilitation and not everybody agreed with such an approach (Smaill, 2003).

In an unpublished paper presented at the First National Conference of the Spinal Network "Life Beyond Bigger!" in 2003, Professor Clarke stressed that successful rehabilitation was hard work, involving personal learning, and was the responsibility of the recovering person. As the major stakeholder in the outcome, the recovering person is the "chairman of directors". Everybody else is "staff". Rehabilitation professionals, programmes, and centres need to recognise this and provide the resources and support to allow it to happen. This involves developing an integrated care model that takes a holistic approach by placing emphasis on the patient as a whole being, giving him or her control and real hope.

This concept originates from the Independent Living philosophy which rejects the behavioural expectations created by both the sick role and the impaired role by indicating that disabled people do not want to be relieved of their family, occupational, and civic responsibilities in exchange for a childlike dependency, but rather they wish to take control of their own life.

This includes the choice to minimise reliance on others in making decisions and performing everyday activities. It includes managing one's affairs, participating in day-to-day life in the community, fulfilling a range of social roles, making decisions that lead to self determination, and minimising physical or psychological dependence on others. The NZST has gone on to become a nationwide organization supporting the concept of independent living and improving the quality of rehabilitation through initiatives and programmes that directly benefit people with SCI (Cassidy et al., 2004; DeJong, 1979, 1985; New Zealand Spinal Trust, 2013; Sinnott et al., 2010).

2.2.2 Older people

The development of the senior rights movement was a global movement, but in this instance the thesis will refer to how the senior rights movement developed in the USA and New Zealand as selected examples. The origins of the senior rights movement in the USA can be traced back to several loosely organised voluntary associations and prominent individuals who advocated for old-age pensions during the 1920s and 1930s. The Townsend movement formed in 1934, by far the largest senior mass-membership organization of the time, marked the beginning of a long line of efforts to organize senior citizens on a national-scale by proposing a federal pay-as-you-go pension. Looking at the USA there are three major organizations which have been involved in developing the senior rights movement the American Association of Retired People (AARP), Alliance of Retired Americans (ARA) and the Gray Panthers. The AARP with its beginnings in the 1950s made popular and rapid advances to become by the mid-1990s one of the largest voluntary organizations active in American politics. With one in every five USA voters belonging to AARP, it has approximately 40 million members over the age of 50 years, half of whom are still actively employed, and hundreds of thousands of volunteers. Its principal aims are to influence the QOL for all people as they age, to lead positive social change and deliver value to members through information, advocacy and service. One of their top priorities in the 1970s was to eradicate the mandatory retirement age. Recently they have focused on ensuring that retirees do not lose their benefits if they choose to remain working. A second organization, the ARA, originally called the National Council of Senior Citizens, began in the 1960s, and has approximately four million members concentrating its efforts on the interests of low income retirees and the protection of all Social Security benefits and national health insurance. Its main goal is to build the most effective organization to advocate for America's senior citizens at national, state and local level. The third organization, the Gray Panthers, began in the 1970s

as an informal group of retirees and young college students has now approximately 20,000 members spread over 50 local networks addressing problems from an intergenerational perspective. Its interests are intentionally wide ranging and include a variety of social concerns, with a commitment to combat ageism and advocate for senior citizens. They concentrate on deconstructing negative stereotypes and replacing them with empowering ones. The Gray Panthers have earned the reputation as being the most radical faction of the senior rights movements in the USA (Beard & Williamson, 2011).

In New Zealand there are two major organizations that have evolved to advocate for older people. Age Concern has its origins in the 1950s when Aged People's Welfare Councils were set up in several cities throughout New Zealand. These Councils acted as coordinating bodies for groups concerned about the elderly and it was not until the early 1970s that a national association was established, known as the National Old People's Welfare Council. This national body was subsequently renamed Age Concern in 1985. In 2008 the brand statement 'Serving the needs of older people' was adopted to summarise its work and aims. Its multi-cultural vision is to have an inclusive society, where older people, koroua and kuia are respected, valued, supported and empowered. It indicates support and promotion for independence, participation, self fulfilment and dignity which it indicates are the cornerstones of the UN Principles for Older Persons. Age Concern supports the concept that ageing is a lifelong process, starting at birth, and that interdependence between the generations is promoted through interactions and educational awareness with younger people working in support of older people. Age Concern New Zealand states that it monitors and responds to Government and non-Government policy development initiatives that impact on older people. It will proactively address issues concern directly with Government or other parties. In its 2012 briefing paper to Government and other parties, entitled. "*What matters to older people,*" four priority concerns are identified - ageist attitude, social isolation and loneliness, being able to afford the basics, and getting the care needed (Age Concern, 2013). In May 1990 Age Concern expressed the political concerns of older people when it issued a 24 point manifesto seeking changes in a range of New Zealand policies affecting its membership. Its actions reflected a movement away from *ad hoc* responses towards more systematic political activity. With the issuing of its manifesto, Age Concern for the first time drew attention to the capacity of elderly people to inflict electoral damage on parties indifferent to their plight (Levine & Roberts, 1993).

Grey Power, originally based in Auckland, was formed in 1986 by superannuitants protesting against the Labour Government's surcharge on New Zealand Superannuation. Grey Power New Zealand Federation Inc. has expanded to 76 associations throughout New Zealand consisting of approximately 90,000 members. Its headquarters remain based in Auckland. It is a lobby organization promoting the welfare and well-being of all citizens in the 50+ years age group with its key aims and objectives being as follows (Grey Power, 2013):

1. To advance, support and protect the welfare and well-being of older people;
2. To protect the right of every New Zealander to have a sufficient superannuation entitlement;
3. To strive for provision of quality health care to all New Zealand residents;
4. To oppose all discriminatory and disadvantageous legislation affecting rights, security and dignity;
5. To be non-aligned with any political party and present a strong united lobby to Parliament and statutory bodies;
6. To promote and establish links with similar organizations;
7. To promote recognition of wide-ranging services provided by senior citizens of New Zealand; and
8. To gain recognition as an appropriate voice for all older New Zealanders.

It lists its achievements as including the removal of the Superannuation Surcharge Amendment of the residential care asset testing legislation, lowering doctors' and pharmacy fees, changes to the over 80 years driving test, superannuation increased to 66% of average ordinary time weekly earnings, improved regulations for rest homes, a rates rebate scheme indexed to the Consumer Price Index (CPI), hearing aid subsidy increase and retention of the SuperGold Card (Grey Power, 2013). The SuperGold Card is a discounts and concessions card for seniors and veterans, in recognition of their contribution to New Zealand society.

Although the political influence of older voters is currently constrained by their size as a proportion of the electorate, both the number and proportion of people aged 65 years and over will grow significantly and increase sharply over the next 40 years. There is solid evidence, both from New Zealand and other parliamentary democracies that older people are more likely to vote than younger citizens. For instance, in the 1999 New Zealand General Election less than 75% of registered voters under the age of 30 years voted (and fewer than 70% of

new voters), whereas nearly 90% of those aged 65 years and over exercised their right to vote (Vowles, 2002). Assuming older people continue to participate more actively in elections than younger adults, by 2050 40% or more of those who actually vote are likely to be aged 65 years and over. This will be a sizable proportion of the electorate and will certainly influence political parties to take into consideration the interests of older people (Boston & Davey, 2006; Levine & Roberts, 1993). Boston and Davey (2006, p. 364-5) suggest that the available empirical evidence (both in New Zealand and elsewhere) indicates that in most situations older voters have widely divergent party preferences and contrasting views on key political issues. People develop party loyalties and issue orientations to varying degrees of intensity and durability, but these tend to be stronger among older voters than their younger counterparts. Older voters tend to have allegiance to a party or political ideas that they typically support throughout their adult life. There is little evidence that older voters define themselves, for political purposes, primarily on the basis of their age or that they strategically block vote on an age-related basis or in relation to a specific generational interest.

With the growing proportion of the population aged 65 years and over it is likely in the future that they will be more politically active than before, with influential interest groups specifically representing older voters. Such activism will no doubt vary over time in response to emerging issues and concerns and in reaction to unwelcome governmental initiatives. Older people in the future will differ from previous generations as they will generally be much better educated, have fewer children, be more likely to be living on their own, and in many cases, be more affluent. This may influence the nature of their political interests and demands. Also the competition between political parties for the 'grey' vote is likely to intensify with specific policies directed towards older voters. The needs of older voters will almost certainly be more prominent (alongside being more diverse) in future government policies especially in the areas of health and disability services, social services, housing, income support, public transport, energy efficiency and pricing and labour market regulation. There will be a greater emphasis on the integration and coordination of services for older people. Population ageing is also likely to contribute to higher levels of electoral support for taxation and public expenditure as older voters are heavily dependent on public expenditure for their income, health care, and social services. It will become increasingly more difficult for governments to make policy changes that may negatively affect older voters such as reducing pensions, introducing means testing, and changing age eligibility thresholds.

The development of political activism amongst disabled and older people in America and in New Zealand highlighted in this section is also similarly occurring in other Western world countries, such as Great Britain and Australia. Each group has separately pursued their own path of development which eventuated with the formation of representative organizations that politically lobbied for specific government policy developments. These key policy developments are now discussed.

2.3 Key legislation and policies from 1970 onwards

2.3.1 Disabled people

From the 1970s, the New Zealand Government's approach to services for disabled people became more community and rights based. For example, following the *1972 Royal Commission into Psychopaedic Hospitals*, government funds were increasingly directed to building small residential facilities rather than large institutions (Office for Disability Issues Ministry of Social Development, 2013). In 1967 a Royal Commission produced the Woodhouse Report which recommended significant changes as to how New Zealand dealt with the consequences of injury. It proposed a move away from a litigious, fault-based system, toward a new 'no-fault' approach to compensation for personal injury. In 1972 a major change to disability support was introduced which affected not only disabled people but all New Zealanders; the *Accident Compensation Act 1972* gave people injured through an accident the entitlement to receive assistance on an individual basis. This came into effect as of 1 April 1974 and was administered by the Accident Compensation Commission, later renamed the Accident Compensation Corporation (ACC). The introduction of this Act was not made retrospective to include people seriously injured prior to 1 April 1974 and this aspect has always been regarded as being unjust by those disabled people in that group. The other major implication of the introduction of ACC was the loss of the right to sue another party for compensation for all accidental injury, regardless of its cause or circumstances. In exchange for losing the right to sue, individuals gained entitlement to a range of rehabilitation services, to lump-sum compensation, and to income support levels in proportion to previous earnings. ACC was initially funded from three sources: motor-vehicle levies, employers and the Government (Barnett & Penny, 2004; Beatson, 2004).

The introduction of ACC highlighted inadequacies in both services and income support for those people injured prior to 1 April 1974 and for people with disabilities due not to injury but to illness or congenital disorder. The *Disabled Persons Community Welfare Act 1975*

(DPCWA) improved both income benefits and community support services and would structure disability welfare for the next 20 years (Barnett & Penny, 2004; Beatson, 2004; Office for Disability Issues Ministry of Social Development, 2013).

During the 1980s and 1990s both the disability support and ACC systems experienced considerable change at the hands of two reforming Governments. Between 1984 and 1990 the Labour Government reformed the public sector. This Government was followed by a more radical National Government (1990 to 1999) seeking to privatise health and welfare services. Prior to 1993, responsibilities for services were divided between the Departments of Social Welfare and Health, with some programmes being demand driven and others being financially capped. From 1993-1995, under the National Government, services were consolidated under the Ministry of Health (MoH). The disability support services (DSS) contained in the *Health and Disability Services Act 1993* moved responsibility for disability policy, funding, and services from the social and welfare sector to the health sector with programmes administered by four regional health authorities (RHAs) and with an emphasis on needs rather than service entitlement. This was debated and criticised by many in the disability community as it was considered it would medicalise them in the eyes of the public. An alternative proposal was suggested whereby there would be a stand-alone enterprise under the control of disabled people who would define, implement, and monitor service delivery in partnership with nondisabled professionals and service workers. Such a proposal was considered too threatening to and rejected by the Government (Barnett & Penny, 2004; Sullivan & Mumford, 1998).

From 1974 to 1984, ACC accumulated considerable reserves to fund future costs of injuries already incurred. Employers, as significant contributors, opposed this build up of reserves and persuaded the then Labour Government to reduce employer contributions, resulting in the reserves eventually being run down to the stage where a pay-as-you-go system developed. The 1990 elected National Government legislated to introduce the *Accident, Rehabilitation and Compensation Insurance Act 1992* which abolished lump-sum compensation for pain and suffering and loss of enjoyment of life; abolished earnings-related compensation and replaced it with a small independence allowance of up to \$40 per week depending on the level of permanent disability sustained; introduced work capacity testing to assess whether a claimant could return to work, with weekly compensation ending if deemed fit to work, whether there was a job or not. This was particularly focused on claimants with long-term injury in an attempt to remove them from ACC compensation and shift people onto the unemployment

benefit. This often resulted in people appealing ACC decisions and caused considerable negative publicity in the wider community, being regarded as unfair. The Government also introduced a new levy on wages for non-work-related accidents and a two cents per litre petrol levy to fund MVAs. The *Accident Insurance Act 1998* further allowed privatisation by allowing employers to purchase cover from accident insurance providers other than ACC (Barnett & Penny, 2004; Sullivan, 2011). In 2000, the newly elected Labour-Alliance coalition Government repealed the *Accident Insurance Act* and restored ACC as the sole provider. The *Injury Prevention, Rehabilitation and Accident Compensation Act 2001* restored lump-sum payments and focused ACC on injury prevention and rehabilitation but did not remove work capacity testing or the wages and petrol levies (Barnett & Penny, 2004; Beatson, 2004; Sullivan, 2011).

In 1999 the Labour-Alliance coalition Government established a new position of Minister of Disability Issues with the responsibility to administer all things to do with disability including policy development, implementation and monitoring. Responsibility for disability was shifted from the Ministry of Health to the new Office of Disability Issues (ODI). A Disability Strategy sector reference group was set up consisting of disabled people, sector representatives and academics and after an extensive consultation process a draft disability strategy was developed. In April 2001 the *New Zealand Disability Strategy: Making a World of Difference Whakanui Oranga* became official Government policy. The ODI, which is part of the Ministry of Social Development, was officially established in 2002 and given the responsibility to implement the Disability Strategy, review legislation in light of the strategy, and to develop policy (Garlick, 2012; Ministry of Health, 2001; Sullivan, 2011).

The New Zealand Disability Strategy (NZDS) is based on a social model of disability rather than a medical model. The NZDS (Ministry of Health, 2001) states that disability is not something individuals have; individuals have impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments. Disability is the process which occurs when one group of people creates barriers by designing a world only for their way of living, taking no account of the impairments other people have. Underpinning the NZDS is a vision of a fully inclusive society which also involves recognising the principles of the Treaty of Waitangi. The strategy states New Zealand will be inclusive when people with impairments can say they live in:

“A society that highly values our lives and continually enhances our full participation.”

(Ministry of Health, 2001)

To achieve the vision of advancing New Zealand towards a fully inclusive society, the NZDS consists of 15 objectives, underpinned by detailed actions. The objectives are to:

1. encourage and educate for a non-disabling society;
2. ensure rights for disabled people;
3. provide the best education for disabled people;
4. provide opportunities in employment and economic development for disabled people;
5. foster leadership by disabled people;
6. foster an aware and responsive public service;
7. create long-term support systems centred on the individual;
8. support quality living in the community for disabled people;
9. support lifestyle choices, recreation and culture for disabled people;
10. collect and use relevant information about disabled people and disability issues;
11. promote participation of disabled Māori;
12. promote participation of disabled Pacific peoples;
13. enable disabled children and youth to lead full and active lives;
14. promote participation of disabled women in order to improve their quality of life; and
15. value families, whānau and people providing ongoing support.

Ministries, departments and Government agencies are required to report in their annual reports to Parliament on progress that has been made in implementing the NZDS. Each year a work in progress report from the Minister for Disability Issues is presented to Parliament outlining progress. Overall there appears to be broad cross-party support for the NZDS. The 2012 progress report, *‘Achieving a fully inclusive society 2012’* comments that there has been some real progress made over the last decade in the implementation of the NZDS, as well as meeting human rights commitments under the UN Disability Convention. Real progress has been made in communication technology, models for supporting disabled people, in support for family carers, in inclusive education and in access to information, particularly in the

online and digital environment. However, there is a shortfall on how Government agencies gather and report disability related information and collect national data and statistics relating to disabled New Zealanders. (Beatson, 2004; Ministry of Health, 2001; Office for Disability Issues, December 2005; Office for Disability Issues Ministry of Social Development, 2012; Sullivan, 2011).

Following the NZDS, a number of reports and initiatives have been launched aimed at removing barriers for disabled people. This includes the report *To Have an 'Ordinary' Life, Kia Whai Oranga 'Noa'* (National Advisory Committee on Health and Disability, 2003) which has 23 recommendations for improving the lives of intellectually disabled adults, concentrating on needs assessment, service coordination and purchasing; moving away from a custodial ownership model of service delivery; and addressing the neglect of basic health needs. In 2006 the *New Zealand Sign Language Act 2006* was introduced recognising New Zealand Sign as New Zealand's third official language. This gave deaf people the right to use New Zealand Sign in legal proceedings and set out principles to guide Government departments in consulting with the deaf community. The *Disabled Persons Employment Promotion Repeal Act 2007* was passed giving disabled people access to the same employment conditions, rights, and entitlements as other New Zealanders. In March 2007 New Zealand signed the *United Nations Convention of the Rights of Persons with Disabilities 2007*. The Convention was developed over six years following a proposal from Mexico to promote and protect the rights and dignity of persons with disabilities. What is interesting is that during these negotiations, New Zealand was the only official delegation to include disabled people. Individualised funding, which is an allocation of hours specifically for disability support services, started as a pilot in 2003 and was administered by the MoH. As a result of a review in 2008 the eligibility for individualised funding was extended and the number of providers increased (Ministry of Health, 2010; Office for Disability Issues Ministry of Social Development, 2013; Sullivan, 2011).

2.3.2 Older people

In New Zealand, government social policy relating to older people has centred on superannuation which, until recently, was used like a 'political football' by various political parties and Governments. In 1972 a Royal Commission on Social Security recommended higher pension levels and similar increases for other benefits. By 1976 the age benefit for a couple had risen to over 70% of net ordinary wages. In 1975 the Labour Government set up a

compulsory contributory superannuation scheme which was to see combined rates for employees and employers to be phased up to eight percent of earnings, funding individual contributions related pensions at retirement. This contributory scheme was short-lived (Fine & Keeling, 2010; Levine & Roberts, 1993).

In the 1975 general election the National Party deliberately targeted retirees and those nearing retirement by offering a generous taxable universal retirement income at age 60 years (down from 65 years). In 1977 the new superannuation scheme was introduced with the superannuation for a couple set at 80% of the average wage and for a single person at 60% of the married pension. No income or asset testing was required. In 1976 the Taskforce on Economic and Social Planning recognised there was a conflict between perceptions of basic entitlement and overriding economic constraint in regards to increased expenditure on national superannuation. This was highlighted when between 1975 and 1977 the number of people receiving the public superannuation rose 28% (due to the drop in age eligibility) and had become the most costly single component in the Government budget. This resulted in increased overseas borrowing and initiatives by successive Governments to trim the cost of the new superannuation scheme and remove tax concessions for private provision. This policy shift was an attempt to address the concerns about the affordability and sustainability of the public superannuation system.

In 1985 the Labour Government introduced a taxation surcharge on other income of superannuitants (Preston, 2008). In April 1988 a Government appointed Royal Commission on Social Policy drew attention to not only the financial dilemmas associated with retirement but also the larger questions of equity and self-image that loss of employment brings when a person retires. The commission concluded that older New Zealanders were not enjoying the respect and dignity to which they were entitled. The Treasury has recently stated in a discussion paper titled '*Affording Our Future*' (The Treasury, 2013) that there will be increasing fiscal pressures from New Zealand Superannuation and the public health care system to which the Government will have to respond, and has urged a national debate on how to best confront the fiscal pressures growing in these two areas of concern. The percentage of nominal Gross Domestic Product (GDP) is projected to increase for New Zealand Superannuation from 4.3% in 2010 to 7.2% in 2050 and for health care from 6.8% in 2010 to 9.9% in 2050 (The Treasury, 2013). Over half of the total expenditure on Social Welfare in the 1990s was going on the Guaranteed Retirement Income.

In early 1990 the Labour Government identified the needs of older people as a substantive policy area by establishing a Minister for Senior Citizens with the role of empowering older citizens, often regarded as marginal. In the October 1990 election the National Party stated it would retain the Senior Citizens portfolio as well as promising to reinstate national superannuation as a universal taxpayer funded pension payable to all eligible citizens regardless of income, and to repeal the National Superannuation surcharge in its first budget. The realities of the economic situation meant National's pre-election promises could not be fulfilled. The surcharge on superannuation was not removed and also it was announced that the age for receiving superannuation would be raised from 60 to 65 years of age over a 10 year period instead of the 20 year plan promised in the election campaign. This caused considerable criticism especially amongst older voters, so much so that three months later the budget night superannuation package was reversed. The only new feature was an increase in the level of surcharge to 25%. Subsequent attempts to develop a bipartisan approach to superannuation have failed (Garlick, 2012; Levine & Roberts, 1993; Ministry of Social Development, 2003).

The New Zealand First party, since its formation in the early 1990s, has consistently advocated policies designed to advance older voters' financial and other interests. This approach has met with some success with the party capturing a disproportionate share of the older age group vote in some electorates and winning some notable policy concessions. In 1996 it was able to secure a coalition agreement with the National party that included a range of measures to assist older people, such as the removal of the New Zealand Superannuation tax surcharge from 1 April 1998, adjustment of asset testing thresholds for long-stay geriatric private hospital care services, and increased funding to reduce waiting times for non-urgent surgery. In 2005 New Zealand First again negotiated concessions to benefit older voters as part of its agreement on confidence and supply with the Labour-led Government, such as increasing the rate of New Zealand Superannuation to 66% (from 65%) of average ordinary time weekly earnings, measures to enhance the provision of elder care, and the introduction of a Seniors' Card more commonly known now as the 'Gold Card' which enables the holder to certain public sector entitlements and commercial discounts. The Labour Government also introduced the *KiwiSaver Act 2006* to encourage New Zealanders to voluntarily save for retirement. The employee was able to contribute up to 8% of their gross pay with the employer contributing up to a maximum of 4%. People also received a \$1000 tax-free contribution from the Government as well as a \$1042.86 tax credit per annum. When National

came into Government in 2008 the employers' contribution was reduced to 2% and employees were allowed to drop their contribution to this level. In July 2011 the annual tax credit was halved to \$521.43 (Barker, 1997; Boston & Davey, 2006; Inland Revenue, 2013; Levine & Roberts, 1993).

The *Human Rights Act 1993* made it unlawful to discriminate against age (Ministry of Justice, 2013). For example older people cannot be forced to retire at a certain age and can work as long as they are competent to undertake the work. In 1999 the United Nations International Year of Older Persons (IYOP) took as its theme: "*Towards a society for all ages*". It promoted positive attitudes to ageing and older people and highlighted the need to prepare for an ageing population. Government funding was provided for community projects and events and 34 Government departments and 45 Crown entities undertook activities which supported the aims of the year. Also the Government funded research to assist policy development to meet the needs of an ageing population (Ministry of Social Development, 2000).

As a result of the 1999 IYOP the Labour Government committed itself to developing a Positive Ageing Strategy. After extensive consultation with local communities, the voluntary sector, and central and local government agencies, the 2001 New Zealand Positive Ageing Strategy was implemented. The aim of the Positive Ageing Strategy is to improve opportunities for older people to participate in the community in ways that they choose by identifying barriers to participation, and working with all sectors to develop actions to address these, while balancing the needs of older people with the needs of younger people and future generations. The strategy recognises that people are not only living longer but are also living healthier lives and can contribute many more years to society. There is increasing ethnic and social diversity, with higher proportions of Māori, Pacific and Asian people who will have different needs and expectations. Future generations of older people are expected to be healthier, more skilled and educated, and remain more active in the workforce than their predecessors.

The reference group working on the 2001 Positive Ageing Strategy developed the following vision:

"Our vision is for a society where people can age positively, where older people are highly valued and where they are recognised as an integral part of families and communities. New Zealand will be a positive place in which to age when older people

can say that they live in a society that values them, acknowledges their contributions and encourages their participation.”

(Office for Senior Citizens Ministry of Social Development, 2013)

In the strategy there are a number of statements that characterise successful outcomes for the vision, such as: society respects older people, values their knowledge, wisdom and skills, and acknowledges the considerable contributions they make to family, whānau and the community; ageing is a positive experience, regardless of gender, age, culture, or ability; older people are able to continue to learn and make the most of their talents, plus many more.

An important part of the Positive Ageing Strategy has been the principles that were adopted after wide community consultation and feedback. These principles are reflected in the ten priority goals set out in the Positive Ageing Strategy, with appropriate actions to achieve these goals. These goals are as follows:

1. Secure an adequate income for older people;
2. Equitable, timely, affordable and accessible health services for older people;
3. Affordable and appropriate housing options for older people;
4. Affordable and accessible transport options for older people;
5. Older people feel safe and secure and can age in place;
6. A range of culturally appropriate services allows choice for older people;
7. Older people living in rural communities are not disadvantaged with accessing services;
8. People of all ages have positive attitudes to ageing and older people;
9. Elimination of ageism and the promotion of flexible work options; and
10. Increasing opportunities for personal growth and community participation.

In 2002 the Office for Senior Citizens was established within the Ministry of Social Development. The Office is responsible for providing information on the senior citizens sector, promoting and monitoring the Positive Ageing Strategy, and providing services to the Minister for Senior Citizens (Office for Senior Citizens Ministry of Social Development, 2013). Like the NZDS, the Positive Ageing Strategy requires government departments and ministries to undertake and coordinate annual action plans regarding the strategy which then

are monitored and reported on annually to Parliament. In addition to the on-going monitoring of specific work items, a report is published approximately every three years on the situation of older people and on positive ageing in New Zealand. The objective of this status report is to provide a summary of the situation regarding older people in New Zealand and identify issues requiring government action as part of the ongoing Positive Ageing Strategy (Office for Senior Citizens Ministry of Social Development, 2013). The latest report summarising the achievements of departments and ministries in relation to the goals was in 2010. The current Minister for Senior Citizens has identified three priority areas: employment of mature workers; changing attitudes about ageing; and protecting the rights and interests of older people such as raising the issue of elder abuse and neglect (Office for Senior Citizens Ministry of Social Development, 2013).

With the concept of 'Positive Ageing' there has been success in moving away from a negative view of old age, calling on older people to be active after retirement, and be in paid or unpaid work, to engage in health-sustaining activities and to be as self-reliant and involved as much as possible. How much this will influence older people has yet to be determined (Boston & Davey 2006).

2.4 Conclusions

The political activism of people with disabilities and older people has developed differently as the two separate groups have pursued their own specific concerns and issues. However, in New Zealand, these pathways of political and policy development have followed very similar timelines, and have been shown also to follow international trends. Despite this, there appears to have been limited recognition, communication or cooperation between organizations representing disabled people and older people. In New Zealand there has been little recognition by the organizations representing disabled people that the people they are representing are living longer and becoming older. Likewise, organizations representing older people appear not to have recognised that there is a group of long-term disabled people who are now becoming old. In part, this may be an unintended consequence of the focus on 'positive ageing', involving a denial of age-related disability. Each group of people has nevertheless followed their own separate political agendas with relative success, and has contributed to the development of national strategic statements.

The introduction of ACC in April 1974 affected everyone in New Zealand with the loss of ability to sue another party for compensation for accidental injury regardless of its cause or

circumstances. On the positive side people gained entitlement to a range of rehabilitation services, lump-sum compensation and income support in proportion to previous earnings. Since the original concept of ACC was introduced there have periodically been policy changes which have affected entitlements, however overall the original concept essentially remains intact. The DPCWA introduced in 1975 was meant to improve income benefits and services for non-injured disabled people and those injured prior to 1 April 1974. In reality the provisions of the DPCWA have never been able to match the compensation and services that disabled people receive under ACC. Those disabled people under the DPCWA are still considerably disadvantaged compared to injury related disabled people covered by ACC.

Eliminating the ability to discriminate by disability and age under the *Human Rights Act 1993* was a major advance in the rights of both disabled and older people. The development of the NZDS and the Positive Ageing Strategy in 2001 has been well received by disabled and older people and the organizations representing them. It is a recognised strength of both strategies that government departments and ministries are required to report annually on how they are progressing in relation to the goals stated in both strategies. There appears to be multi-party political agreement on the goals of both strategies.

With the number of people aged 65 years and over increasing to the extent that by 2050 40% of the population will be in this age bracket, political, fiscal and policy debates can be expected to continue. However, New Zealand has throughout retained the principle of universal entitlement to New Zealand Superannuation, which is itself a significant inclusive statement (Fine & Keeling, 2010). There appears to be little recognition by either disabled people or older people and the organizations representing them that ageing disabled people are part of the increasing diverse population of ageing people.

Set against this broad overview of political activism amongst disabled and older people in New Zealand which has played an important role in influencing the development of key government legislation to make New Zealand a more inclusive and diverse society, the next chapter reviews the literature associated with ageing with SCI and how it specifically relates to the development of secondary conditions and associated implications.

Chapter 3: Literature review: Ageing with spinal cord injury

3.1 Introduction

In the late 1980s and early 1990s SCI physicians and other interested health professionals started to realise how ageing was affecting both those with SCI and the services that supported them. Key issues were identified and comprehensive research specifically investigating aspects of ageing began. In an edited book from invited authors from a variety of backgrounds, Whiteneck et al. (1993) attempted to explore the interface between SCI and ageing through multiple perspectives, including research, physiological, psychosocial and survivor perspectives, societal perspectives, the providers' perspectives and projections into the future. Since then there have been a number of longitudinal (Charlifue, 2007; Charlifue & Gerhart, 2004; Charlifue et al., 1998; Charlifue et al., 2004; Coll, 2007; Crewe, 1997; Krause & Broderick, 2005; Krause & Sternberg, 1997; McColl M.A. et al., 2003; Weitzenkamp et al., 2001) and cross-sectional studies (Adkins, 2004; Bushnik et al., 2007; Forchheimer & Tate, 2007; Hitzig et al., 2008; Krause, 2007; Liem et al., 2004; McColl et al., 2003; McColl et al., 2004; Petrofsky & Laymon, 2002; Whiteneck et al., 2007; Winkler, 2002) which have enabled a better understanding to develop on the ageing of SCI people. It is now known that the development of secondary conditions and the length of time since initial injury can have a major impact on the health of people with SCI as they age.

Life expectancy, mortality and morbidity have changed dramatically over the last 30 years (Capoor & Stein, 2005; Groah et al., 2012; Kemp et al., 2004), although there is increasing evidence of secondary complicating factors which can have a major impact on those ageing with a SCI or condition. This includes physical changes and deterioration which occur over time affecting health-related quality of life (HRQOL), and the ways individuals cope with their disability long term.

Longitudinal studies that measure changes over time are generally regarded as the most appropriate research design for studying ageing. However, Krause and Sternberg (1997) suggest such longitudinal designs can confound ageing with time period, so that observed change between two repeated measurements (eg. 1980 and 1990) may be caused by environmental change, rather than ageing itself. In addition, there is the logistical difficulty in

studying a group of participants over an extended period (eg. deaths, withdrawals, incomplete data collection, and non-response). Also cost is an issue in longitudinal studies, as it requires a management and organizational structure over a long period of time which often exceeds funding organizations' timeframes. Cross-sectional studies are the most commonly employed methodology. This research design allows associations between age, time since injury, and adjustment at a given point in time to be measured (DeVivo, 2004), but it does not indicate how adjustment changes over time or how environmental changes affect adjustment. Causality can sometimes be difficult to resolve, potentially causing ambiguity (Koepsell & Weiss, 2003). A key factor is that the sample should be large enough to represent the population and estimate the prevalence of variables of interest (Hennekens & Buring, 1987; Koepsell & Weiss, 2003).

This chapter has been set out to give the reader an overview of the literature defining SCI, and the research literature investigating: life expectancy, mortality and morbidity in the SCI population; premature ageing; the development of secondary conditions which relate to changing physical, psychosocial and QOL issues; and environmental factors that influence ageing with SCI. Key issues in the literature that relate to the doctoral thesis research are discussed in the conclusions.

The search method for the collation of the literature on ageing with SCI initially started with undertaking a general scan of literature relating to 'disability', then combining this with 'ageing'. Once a general understanding was obtained about the issues and implications of ageing with a disability, the literature search was refined to scan for publications and articles specifically relating to 'ageing' and 'spinal cord injury' and 'spinal cord impairment', many of which are included in this current literature review. As the doctoral research project developed a clear research methodology, the literature review on ageing with SCI was regularly updated as specific areas of interest arose and required more in-depth review. The online databases selected for regular scanning were OVID (including MEDLINE, EMBASE, NURSING, and PsychINFO), Ebsco (includes CINAHL), PubMed, and Science Direct.

3.2 Spinal Cord Injury

SCI occurs when there is damage to the spinal cord that blocks communication between the brain and body. Figure 3.1 details the neurological levels of the spinal cord in relation to the bony vertebrae levels of the spine (Apparelyzed. Spinal Cord Injury Peer Support, 2013). SCI can be a break, tear, rip or crush caused by physical force and described as a traumatic lesion.

SCI can also include damage to the spinal cord through diseases (i.e. neoplasms, vascular disease, inflammatory disease and spinal stenosis) (Ho et al., 2007). SCI is related to the nerves that are damaged but can also refer to the level of bony injury. It is more accurate to refer to the actual area of the spinal cord that is damaged relative to the vertebrae i.e. C5/C6 tetraplegia. Depending on the level and type of injury, neurological impairment can cause muscular weakness, paralysis, loss of sensation and bladder and bowel control. Motor messages are unable to pass the damaged area so the brain cannot control the muscles and sensory messages beyond the place of injury. Reflex messages may still be able to loop from the spinal cord to the brain which can no longer dampen the reflex movements, a process which often results in muscle spasm. SCI does not prevent the muscles and organs below the level of injury receiving blood and nutrients, but it may affect breathing, temperature control, heart rate and blood pressure, as well as bowel, bladder and sexual function (Verkaaik, 2004). SCI is described as being complete when the spinal cord is totally severed, or incomplete when the spinal cord is not completely severed, but which can result in possible loss of muscle movement and/or sensory sensation below the level of injury.

Thirteen studies reviewed by van den Berg et al. (2010) showed annual incidence rates of SCI ranging from a relatively low 12.1 per million in The Netherlands to a relatively high 57.8 per million in Portugal, indicating the variation in Western Europe. North American studies revealed annual rates between 25.2 and 52.5 per million. Other national annual incidence rates included 18.8 per million reported in Taiwan; between 12.7 and 16.9 per million in southeast Turkey; and 14.5 per million in Australia. Most studies describe a bimodal distribution with the first peak being young adults and between 15 and 29 years, with the most common second peak occurring among older (mostly aged ≥ 65 years) adults. In one study of non-traumatic SCI, the incidence rate increased steadily with advancing age. It was suggested this could be due age-related conditions, such as tumours, degeneration or vascular problems (New et al., 2002). In traumatic SCI, the sex ratio ranged considerably, from 2 Male (M):1Female (F) in Turkey to 6.7M:1F in Ireland. In contrast, a lower sex ratio of 1.3M:1F was reported for non-traumatic SCI.

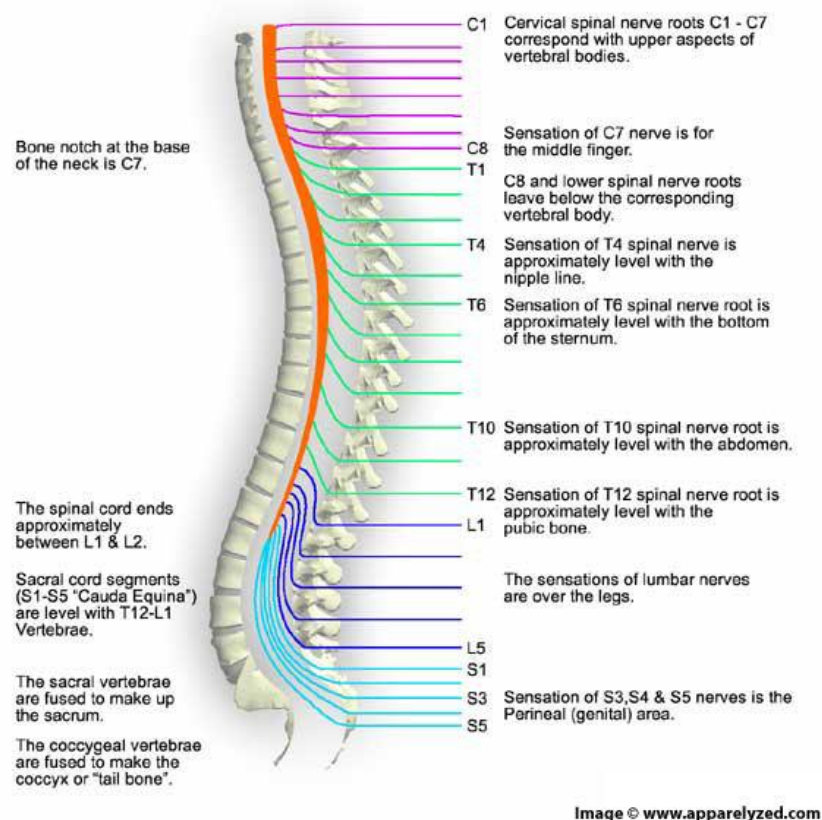


Figure 3.1 Diagram of spinal cord

(source: Apparelyzed. Spinal Cord Peer Support, 2013)

It was concluded that the major methodological differences between the reviewed studies make accurate comparisons challenging. However, the results do show changing epidemiological patterns in SCI, with a trend to increased traumatic and non-traumatic incidence in the elderly. Van den Berg et al. (2010) suggest that prevention of SCI should not only focus on young males but also on older adults who show peak incidences mainly resulting from falls. It is predicted that the worldwide population aged 65 years or older will increase from 8% of the world's population in 2010 to nearly 16% of the world's population in 2050, with most of that increase taking place in developing countries. Consequently, an increase in incidence of non-traumatic SCI is anticipated with major implications for the organization and delivery of care and community services. Wyndaele and Wyndaele (2006) reviewed two studies from Australia and Finland on the prevalence of SCI and 17 studies (seven European, five North American, four Asian and one Australian) on the incidence of SCI. They found the incidence of SCI was between 10.4 and 83 per million, that one third of people with SCI were reported to be tetraplegic, and that 50% of patients had a complete

lesion. They concluded that the reported incidence and prevalence have not changed substantially over the past 30 years, suggesting a need for the development of uniformity in methodology to improve data reliability.

In studies undertaken in North America, Europe, Asia and Australia, MVAs in the age group 15 to 44 years were the most common cause of SCI, followed by falls predominantly in the over 60 years of age group; however, the number of falls in the older age groups are increasing (Burt, 2004; DeVivo, 2012; Ho et al., 2007; Jackson et al., 2004; van den Berg et al., 2010).

Data analysed from the American-based National Spinal Cord Injury Database (NSCID) set up in 1973, which has been collecting data on people with new SCIs from the facilities participating in the Model Spinal Cord Injury System (MSCIS), found that between 1973 and 1979, the average age at injury was 28.7 years, with most of the injuries occurring between the ages of 16 and 30 years. The average age at injury has since increased to 38 years in 2000 and was approximately 40 years between 2005 and 2009 (Groah et al., 2012). Furthermore, there was an increase in the percentage of cervical injuries from 53.5% of all injuries between 1973 and 1979 to 56.5% between 2000 and 2003. The sex ratio was 4M:1F (Ho et al., 2007; Jackson et al., 2004). When reviewing the 17 studies on the incidence of SCI, Wyndaele and Wyndaele (2006) found that the mean age at time of injury was 33 years and the sex ratio was 3.8M:1F.

Regarding incidence rates of SCI in New Zealand, Dixon et al. (1993) reviewed Health Statistics Services morbidity data and concluded that in 1988 the incidence rate of SCI was 49.1 per million people, with young males between the ages of 15 to 29 accounting for 46% of all SCI. The male SCI rate was 71.9 per million whereas the female rate was 26.0 per million. The standardised age/sex/ethnicity rates showed a higher rate for Māori males in the 15 to 35 and 45 to 65 years age groups. MVA (54%) were the leading cause of SCI followed by falls (24%). Derrett et al. (2012), collecting demographic and clinical data on all people admitted to New Zealand's two spinal units from 2007 to 2009, concluded that annual incidence of SCI (traumatic and non-traumatic) was 30 per million. They suggest that differences between the two studies were related to the method of ascertaining the information. Dixon et al. (1993) used all hospital admissions for SCI with and without evidence of vertebrae fracture whereas Derrett et al. (2012) excluded people who had died before being admitted to a spinal unit or were not New Zealand residents. Compared with

Europeans (29 per million), the incidence of SCI was high among Māori (46 per million) and higher amongst Pacific people (72 per million) (Derrett et al., 2012).

3.3 Life Expectancy, Mortality and Morbidity

Until the mid-twentieth century the life expectancy of people with SCI was relatively short, with people commonly dying as a result of renal failure and infection. Capoor and Stein (2005) comment that over the past 25 years urinary tract complications have been reduced to the point where renal failure accounts for only 2.3% of deaths amongst people with SCI. Improved survival following SCI can be attributed to the introduction of antibiotics, advances in long-term health interventions, and the availability of preventive care at specialised treatment units. Life expectancy after SCI is approximately 85% to 90% that of non-disabled people, depending on the degree of neurological impairment and the age at the onset of injury. It is further suggested by Capoor and Stein that there has been a 2000% increase in the post-SCI life expectancy in the past 50 years, in comparison to a 30% increase in life expectancy for the non-disabled population.

A study undertaken by Frankel et al. (1998), reviewing medical records over a 50 year period at two spinal units in Great Britain, indicated that higher mortality risk was associated with higher neurological level and completeness of injury, older age at injury, and earlier time after injury. Individuals with high tetraplegia are less likely to have a long life, with the leading cause of death being respiratory complications. The leading causes of death for paraplegics are heart disease and cancer (Adkins, 2004; Capoor & Stein, 2005; DeVivo, 2004; DeVivo et al., 1999). Improved life expectancy has been associated with improved trauma and rehabilitation care, along with outpatient care, research and prevention. As a result, the average age at injury and the average age of the SCI population have both increased; however, SCI does seem to have a detrimental effect on life longevity (DeVivo, 2012; Groah et al., 2012; Kemp et al., 2004).

DeVivo (2012) after undertaking an extensive literature review of all relevant studies of the descriptive epidemiology of traumatic SCI, concluded that the average age of a newly injured persons and all persons who are currently alive with SCI will increase slowly. The percentage of new injuries occurring among people aged 60 years and older will increase, but the percentage of overall people with SCI aged 60 years and older will increase more slowly because of the high mortality rates among older persons with SCI. Similarly, the percentage of higher injury levels will increase among new injuries but remained relatively stable in the

overall SCI population. Shavelle et al. (2015) suggest there is no evidence that long-term survival in people with SCI has improved over the last 30 years. The authors suggest mortality in the general population has steadily decreased over time. As a consequence, the standardised mortality ratios for people with SCI relative to the general population have actually increased significantly since the 1970s. This was based on analysing information from participants from the MSCIS who were people with SCI, had survived two years post-injury, were older than 10 years and did not require ventilator support.

Rabadi et al. (2013) undertook a retrospective analysis of 147 USA veterans with traumatic SCI and concluded at the end of the 12 year study period that 60% had survived. The sample, almost all male (144 of the 147) had an average age of 59.6 years and average duration of SCI of 24 years. There were three major causes of death, infection related such as pneumonia (21%), urinary infection (14%) and infection of pressure ulcers (11%); cardiovascular-related complications such as congestive heart failure (16%), coronary arterial disease (13%), and atrial fibrillation (2%); and cancer related (16%) conditions. It was also concluded that each additional year of age at the time of injury was associated with a 9.7% increase in the likelihood of death. Therefore being older at the time of injury was a significant predictor of SCI-related mortality with people with SCI more likely to die from cardiovascular deaths than the general population. Injury severity, vascular risk factors, pressure ulcers and neurogenic bladder and bowel were not significant predictors.

Yu et al. (2008) analysed the end of life health care costs and medical conditions of veterans with SCI. Subjects were USA veterans who used the Veterans Association (VA) healthcare system in the USA during the final 24 months of their life. Level of impairment was classified as traumatic injury (68.1%) and non-traumatic (31.9%), with 52.6% being paraplegic and 47.4% being tetraplegic with 98.6% of the veterans being male. The average age at onset of injury/disorder was 42 years and at death was 66 years. Subjects with traumatic injuries had an average age at injury of 40 years and their average age at death was 65 years. Subjects with non-traumatic injuries were significantly older at the time of disease onset (55 years) and at death (69 years). Yu et al. concluded that the cost of caring for veterans with SCI near the end of their lives was considerably higher than reported VA costs of veterans in the general population, although the costs only escalated in the final three to six months before the end of life. Conditions that accounted for the greatest costs included major medical conditions, such as cancer (20.9%), influenza/pneumonia (15.1%), and heart disease (13.5%); followed by other conditions such as septicaemia (5.9%), stroke (5.1%), chronic obstructive pulmonary

disease (4.5%), and diabetes (5.3%). The two leading causes of death in the USA between 2001 and 2004 were heart disease and cancer. It was suggested that veterans with SCI were dying from the same causes as the general population. The authors pointed out the following limitations of the study: 1) the results may not be able to be generalised to non-veteran persons with SCI; 2) results may not be applicable to women; 3) the study only reported VA costs; and 4) etiology data were missing for a substantial number of veterans.

3.4 Premature Ageing

Originally it was considered that SCI was a stable condition. It is now generally accepted by both researchers and physicians who treat SCI that it is a dynamic condition which changes over time. It has been suggested that the rate and effects of normal ageing are accelerated in individuals with SCI (Capoor and Stein, 2005; Kemp et al., 2004; Jensen et al, 2013). These authors note that clinicians treating people with SCI have noticed evidence of ‘premature ageing’ or ‘accelerated ageing’ similar to that described in polio survivors and persons with other chronically disabling conditions. Factors that can affect the speed and extent of ageing with SCI include: neurological level, extent and duration of injury, age at time of injury, weight, pre-morbid health history, medical co-morbidity, gender, ethnicity, and the success of rehabilitation at time of injury. Also there is the complex interaction of genetic factors, lifestyle, adaption to stress and social roles, alterations in living situation and family structure, and potential depletion of social and economic resources (Adkins, 2004; Capoor & Stein, 2005; Groah et al., 2012; Jensen et al., 2013; Kemp et al., 2004).

Capoor and Stein (2005) comment that the biological capacity for able-bodied people plateaus at about the age of 25 years, and then the function of the internal organ systems start to decline by about 1% per year. Kemp et al. (2004) suggest that this starts at about the age of 20 years, with there being a gradual reduction in function after that age. In Figure 3.2 Adkins (2004) shows the impact SCI might have on the normal ageing model for a biological system, with earlier the onset of SCI leading to earlier decline. Adkins (2004) suggests this 1% capacity decrease per year continues, leaving about 50% reserve capacity. It is believed that when the reserve capacity drops below 40%, biological systems become more vulnerable to ‘insults’ (e.g. low impact falls resulting in fractures, influenza leading to pneumonia, unusual physical exertion leading to heart attack). In this model, early age onset, before the end of development and peak capacity has been reached, has a greater impact than onset at an age after peak capacity has been reached.

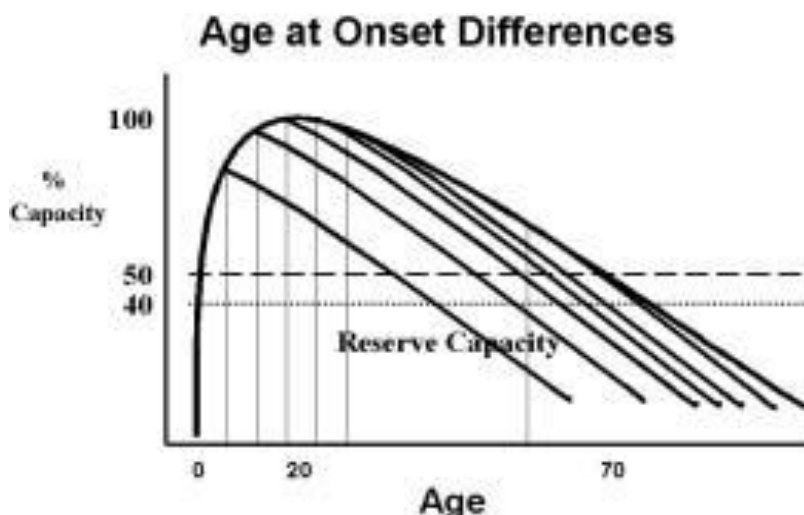


Figure 3.2 Age at onset of SCI

(Reproduced from Adkins, R. H. 2004)

The impact decreases as the injury occurs later on the age continuum. At the far end of the continuum, since capacity is already low, only a slight change in rate will push reserve capacity below 40% soon after injury. Adkins suggests that the age at which the injury occurs plays a role in the process of biological deterioration, especially when the onset age is prior to physical maturation. Capoor & Stein (2005) support this theory by suggesting that there is evidence that individuals injured at a young age enjoy a maintenance phase of 20 years or more before experiencing functional decline, whereas individuals who are 55 years or older at the onset of spinal cord injury have 5 to 7 years of relatively stable functioning before experiencing decline. The level of injury can also affect the decline, with tetraplegics requiring additional assistance earlier than paraplegics due to functional changes. Rodakowski et al. (2014) found the older the age was at the time of injury, the greater the influence age had. The older someone was when they sustained the SCI, the more rapid their disability increased over time. Whereas the younger the person was when sustaining the SCI, the slower the disability increased as they aged. The authors suggest those people who sustained their SCI at a younger age adapt to their disability better.

With changes and developments in medical knowledge and technology, as well as attitudinal changes within society, people with SCI live much longer and remain active members in society. Research indicates that people ageing with SCI experience changes and deterioration in both physical and psychological well-being. McColl et al. (2003) summarise this well, indicating that there are at least five types of changes that people with SCI will encounter as they get older:

1. Shoulder deterioration, chronic bladder infections, and/or postural problems;
2. Secondary complications to the original lesion, such as post-traumatic syringomyelia;
3. Pathological processes not related to be spinal cord injury such as heart disease and other chronic diseases;
4. Degenerative changes associated with ageing such as joint, sensory, and connective tissue problems; and
5. Environmental issues related to society, community and culture.

McColl et al. (2003) based these conclusions on a cross-sectional analysis of data collected in 1999 as part of a longitudinal study researching ageing and SCI involving populations in three countries: USA, Britain, and Canada. The sample consisted of 352 participants, with a mean age of 58 years, average time since injury of 34 years, and 83% were male. The level of injury was 44.1% cervical, 46.3% thoracic, and 9.6% lumbosacral.

Jensen et al (2013) undertook a scoping review of 92 relevant articles and found that the key findings were that (1) there are a large number of serious secondary conditions which occur at a significantly higher rate in persons with SCI then the normative population; (2) the most common conditions are pain, bowel and bladder problems, muscle spasms, fatigue, heartburn and osteoporosis; (3) a number of these conditions such as cardiovascular disease, diabetes, bone mineral density loss, fatigue and respiratory complications occur in older individuals or people with greater SCI duration, compared to younger individuals or those with shorter SCI duration; and (4) there is a lack of longitudinal research looking at the natural course of secondary conditions that develop in people ageing with SCI. What findings there are from the limited studies are often inconsistent with only cardiovascular disease and weight showing increases over time.

3.5 Physical changes and deterioration associated with ageing with a SCI

This section summarises recent research investigations and findings that relate to the physical changes and deterioration associated with the development of secondary conditions that may contribute to the ‘premature ageing’ or ‘accelerated ageing’ of a person with SCI. The development of secondary conditions causes additional physical demands on a person's body often causing deterioration and complications. This physical deterioration and complications can have a major impact on the QOL of a person with SCI, and how they cope with the ageing process.

Neurological and Musculoskeletal Changes

Capoor and Stein (2005) suggest that musculoskeletal pain is associated with injury to the joints and muscles aggravated by movement which will result in local swelling, tenderness, loss of joint motion and instability. Not all pain is mechanical in nature as there are other causes such as referred pain from radiculopathy and syringomyelia. The most common causes of upper body pain are due to a person being required over a long period of time to transfer in and out of a wheelchair, wheelchair propulsion, and the need for regular lifting to achieve pressure relief. The development of muscle imbalance over time can also contribute to shoulder pain. Postural issues may contribute to myofascial pain often characterized by trigger points associated with radiating pain along with numbness. Postural problems may include such things as forward head leaning and scoliosis. Spasm and inappropriate seating during wheelchair propulsion has been recognised as a contributing factor to neck, shoulder or back pain after SCI (Boninger et al., 2003). With people with SCI living longer and having more active lifestyles, there is potential for additional late neurological changes. Late onset of muscle weakness or sensory loss has been reported in 19% of a large sample of people with chronic SCI (Bursell et al., 1999). The findings from the studies reviewed by Kemp et al. (2004) and Capoor and Stein (2005) indicate that ageing with SCI results in greater loss of strength than ageing without SCI. It is unclear whether or not these findings are independent of recently improved treatment regimes and equipment. In a randomised controlled trial which introduced a 12 week home-based exercise treatment programme for paraplegics with shoulder pain, Kemp et al. (2011) demonstrated a significant reduction in pain that increased social participation and improved reported QOL.

A common complication of SCI is osteoporosis below the level of the lesion due to the non-use of the paralysed part of the body, resulting in bone hyper-resorption which occurs most severely in the acute stage of the injury. Capoor and Stein (2005) refer to a study by Garland et al. (1992) which suggests that homeostasis is thought to be reached after about 16 months, with a bone mass two thirds of that of the original. It is recognized that accelerated osteoporosis is a major underlying risk factor for pathological fractures after SCI. Garland et al. (2001) demonstrated that bone loss in the lower extremities of people with complete SCI occurs rapidly, with approximately 25% loss at the hip and 37% loss at the knee within 16 months after injury. They further suggested that there could be an incidence rate of nearly 40% or more for extremity fractures, with the majority of the fractures occurring around the knee.

No treatment has been shown to provide long-term prevention of osteoporosis and it seems that life-style methods of prevention offer the best outcomes, with it being suggested that people with SCI be educated about modifiable risk factors such as transfer methods, caffeine, smoking, and alcohol use. Because of calcium deficiency and vitamin D deprivation may contribute to osteoporosis it is suggested that supplements for both be considered (Bauman et al., 1995; Garland et al., 2001; Nance et al., 1999). Although there is evidence that early mobilisation, weight-bearing exercise or functional electrical stimulation (FES) induced low extremity cycling may be effective in preventing osteoporosis when started within six weeks of the injury. These strategies are not considered particularly effective in increasing bone mass in the chronic SCI population (Nance et al., 1999).

Cardiovascular and Endocrine Changes

It has been found that diseases of the cardiovascular system develop at an earlier age in SCI people than the general population (Bauman & Spungen, 1994; Frankel et al., 1998; Groah et al., 2001). Cardiovascular diseases has steadily risen to be one of the leading causes of death for those people living with long-term SCI, causing more than 20% of deaths in patients enrolled in the American-based National SCI database from 1993 through to 1998 (DeVivo et al., 1999). It has been also suggested that these diseases may contribute to fatigue and weakness which affect QOL. Multiple risk factors have been reported to be associated with developing coronary heart disease (CHD), such as metabolic changes, low high density lipoprotein (HDL), glucose intolerance, and insulin resistance (Bauman & Spungen, 2001a, 2001b; DeVivo et al., 1999). It has been suggested that almost 40% of people with SCI have significantly reduced levels of HDL, with complete tetraplegics having the lowest HDL values and the highest risk for cardiovascular disease (Bauman et al., 1999; Bauman et al., 1992).

Glucose abnormalities generally increase with advancing age in SCI. A high prevalence of muscle weakness linked to the loss of lean body mass (sarcopenia) as a person ages has been strongly associated with disability and the ageing non-SCI population. The rate of sarcopenia has been observed in 3.2% of people with SCI compared to 1% in able-bodied men (Bauman & Spungen, 2001a). Hitzig et al. (2008) found the odds of developing cardiac complications or high blood pressure increased per year with age. Although tetraplegics have low cardiac output and are somewhat protected from developing hypertension by sympathetic under-activity, there is an increased incidence of hypertension in paraplegic men that is related to inactivity and obesity. LaVela et al. (2012), who compared three groups of men 65 years and

over (veterans with SCI, able-bodied veterans, and men from the general population) found the odds of having a stroke was 1.4 times higher for veterans with SCI than able-bodied veterans, and there was also higher odds of a stroke in veterans with SCI than in the general population. However the odds for CHD were significantly lower for veterans with SCI compared to the other two groups, which is generally contrary to what previous literature on ageing with a SCI has suggested. LaVela et al. (2012) recognise that further research is required as their data did not provide information on levels of HDL, an important factor which is recognised as being protective against CHD.

Strategies to reduce the risk of CHD include periodic review of risk factors such as serum lipids, oral glucose tolerance, weight, blood pressure, dietary habits, smoking, activity levels, and alcohol consumption. It has been also suggested that annual electrocardiogram screening is important for those people with higher levels of SCI and/or diabetics as they may not be able to feel the typical symptoms of angina (LaVela et al., 2012; Szlachcic et al., 2001; Szlachcic et al., 2014). SCI may cause reduced exercise tolerance because of the combination of somatic impairment that limits muscle mass available for activation and autonomic impairment that limits the cardiovascular system's ability to respond to the demands of exercise. There is evidence from research that regular physical activity improves physical fitness, glucose metabolism, HDL and psychological well-being of people with SCI (Hicks et al., 2003; Hooker & Wells, 1989; Noreau et al., 1993; Washburn & Figoni, 1999). However their physical limitations and environmental barriers result in fewer options for exercise. What is unclear is the amount of physical intensity required to achieve these beneficial effects (Kemp et al 2004; Capoor & Stein 2005).

Respiratory System Changes

Restrictive impairment that occurs at the onset of SCI is related to respiratory muscle paralysis, as well as the level and the completeness of the injury. The early development of kyphosis, scoliosis or increasing muscle spasm may cause further restriction (Boninger et al., 1998). Reduced lung and chest wall compliance, ineffective cough and inability to breathe deeply can lead to a lack of normal oxygen absorption to healthy tissue (atelectasis) and pneumonia, which historically had been the most common cause of death in all age groups and in all post SCI time periods until recently (DeVivo et al., 1999). Recent cross-sectional research suggests that respiratory function declines with the increasing years since injury and is independent of age, even in paraplegics, and that smoking exacerbates the rate of decline (Adkins, 2004; Hitzig et al., 2008; Linn et al., 2000; Linn et al., 2001). There is a high

incidence of sleep apnoea syndrome (SAS) in tetraplegic men with long-term SCI (Burns et al., 2001). This has been associated with a large neck circumference, long-standing SCI, supine sleep posture, and the use of the anti-hypertensive and antiarrhythmic cardiac medications. Regular monitoring of respiratory function especially for high-level tetraplegics is important (Burns et al., 2001; Stockhammer et al., 2002). The most cost-effective health measure is immunisation. Those SCI persons who are susceptible to respiratory complications are recommended to receive yearly influenza immunisation and pneumococcal vaccination every five years (Capoor & Stein, 2005; Waites et al., 1981).

Urinary Tract Changes

Urinary tract complications have significantly declined as a major cause of death after SCI over the past 25 years (DeVivo et al., 1999). Renal complications in SCI may result from chronic inflammation of the kidney and urinary tract (pyelonephritis), urinary tract calculi, obstruction of the normal urinary outflow (chronic detrusor sphincter dyssynergia), urinary reflux (vesicourethral) (Burton & Vaziri, 2003). Persons with SCI and excessive amounts of protein in the urine (proteinuria) have more impaired renal function and increased mortality compared with SCI patients without proteinuria (Wall et al., 1999). Abnormal renal function testing increases with age and time since injury and is more common in males over the age of 60 years, and in people with greater neurologic impairment, and in those with indwelling catheter use (McKinley et al., 1999). Age and gender are not significant factors in the development of kidney stone disease. The most important predisposing factors for development of stones are recurrent urinary tract infections (Burton & Vaziri, 2003; McKinley et al., 1999). Elmelund et al. (2014) found people with SCI have a steady level of P-creatinine during the first 30 years post-injury then there is a significant decrease until around 45 years post-injury. Both in people with SCI and the general population total muscle mass declines with increasing age. The authors suggest that there is a more extensive loss of muscle mass over time in people ageing with SCI compared to the general population. It was concluded with the decreasing P-creatinine over time in people with SCI that the test is a poor detector of early renal deterioration.

Urinary tract infections remain a common complication in long-term SCI with people averaging 1.6 to 2.2 infections per years (Charlifue et al., 1999). Urinary tract infections are frequently perpetuated by modifiable risk factors such as impaired urinary drainage, the presence of calculi, or the use of indwelling catheters. Bladder cancer incidence and mortality are significantly higher after SCI. A fourfold higher risk of the bladder cancer is strongly

associated with long-term indwelling catheter use although the cumulative effects of recurrent urinary tract infections, cigarette smoking, and urinary tract stones may also contribute (Charlifue & Lammertse, 2002; Groah et al., 2002).

Long-term urological care should include screening for infections, stones, upper urinary tract deterioration and cancer. Education about adequate hydration and compliance with hygienic bladder management is also crucial. Routine use of antibiotics may increase the risk of bacterial resistance and is not recommended (Weld & Dmochowski, 2000; Wyndaele, 2002). Keeping the urine acidic and consuming preventive drinks (such as cranberry juice) can assist in reducing urinary tract infections (Reid et al., 2001).

Bowel and Gastrointestinal Changes

In able-bodied individuals ageing causes decreased secretion of digestive juices, diminished emptying of fluid meals in the stomach, increased intestinal transit times, and diminished gut motility; with an increase in water resorption in the colon, leading to hard stools which can increase the risk of fissures, haemorrhoids, and diverticular disease (Charlifue & Lammertse, 2002). The effect of SCI largely depends on the level of injury. There are those who have a lower motor neuron bowel syndrome (mainly paraplegics) that produces segmental peristalsis, prolonged transit times and constipation, with a high risk of frequent incontinence because of a flaccid external sphincter mechanism. Those with upper motor neuron bowel dysfunction (mainly tetraplegics) have abnormalities involving the entire colon with delayed colon and rectal transit times which produces constipation with faecal retention behind a spastic anal sphincter (Lynch et al., 2001; Stiens et al., 1997). Although it varies, approximately half of long-term SCI people report constipation, incomplete evacuation, and intermittent abdominal distension, whereas approximately one third report gastrointestinal pain and faecal incontinence (De Looze et al., 1998; Fajardo et al., 2003; Harari et al., 1997; Menter et al., 1997).

Diarrhoea alternating with constipation is often related to impaction which may be caused by reduction in activity, diet, inadequate fluid intake, inefficient or infrequent bowel routine, stress and potentially constipating medication prescribed for pain, depression, spasticity and autonomic dysreflexia.

Many people report spending a considerable amount of time on bowel care (Harari et al., 1997). More than one third of people with SCI people rank neurogenic bowel dysfunction as one of the major problems of daily life. Fear of bowel accidents is stated as a common reason

for not engaging in social activities outside the home (Stiens et al., 1997). A key goal of long-term health care management is to achieve predictable complete bowel evacuation and to prevent incontinence and chronic constipation and related complications such as haemorrhoids, fissures, rectal prolapse and proctitis. To achieve this it is important to have a balanced diet, fluid intake, activity level, and medications.

Neurogenic bowel management is affected by age related decline (Capoor & Stein, 2005). There is no convincing evidence that increased dietary fibre results in improved bowel function after SCI (Lynch et al., 2001). Long-term use of enemas and stimulant laxatives should be avoided (Capoor & Stein, 2005). SCI people are considered at equal risk with the general population for colorectal cancer but symptoms such as constipation are much more difficult to interpret. It is suggested that people with SCI should be screened periodically by sigmoidoscopy or colonoscopy every five years after the age of 50 years (Stiens et al., 1997). Another common gastrointestinal complication that may arise due to ageing with SCI is significantly higher prevalence of gallstones or symptoms of abdominal discomfort (Capoor & Stein 2005).

3.6 Quality of life and psychosocial well-being

There is a wide range of interpretations of QOL, especially as it can be interpreted and assessed from an objective or subjective perspective. This section has been separated into two sub-topics, firstly defining the key concepts on QOL in relation to disability (including SCI) and secondly, reviewing specific research on rating QOL in relation to ageing with SCI.

Key concepts of quality of life

Wood-Dauphinee et al. (2002, p 137) describe QOL as representing the widest range of human experience and is composed of all things which individuals' value. They describe the World Health Organization's definition of QOL as being "the individuals' perception of their own position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concern". Yet despite such a statement, and a variety of conceptual models and measures, a precise and universally accepted definition has remained elusive (Albrecht & Devlieger, 1999; Wood-Dauphinee et al., 2002). The concept of QOL can be approached either objectively or subjectively. Objective QOL refers to tangible entities such as employment, income, marital status, home ownership and educational level. Subjective QOL refers to the person's own view or rating of his or her

QOL. Often there appears to be little correspondence between objective and subjective QOL for a given person (Dijkers, 1997; Kemp et al., 2004).

Kemp et al. (2004) suggest that there is a perceived stereotype that people with SCI must have lower QOL than people without SCI. Dijkers (1997) concluded in a meta-analysis of 22 studies, with an average sample size of 102 participants that people with SCI tend to report lower subjective well-being than non-disabled people. Dijkers suggested a need for longitudinal research to investigate subjective well-being in persons with disabilities in more detail. Capoor & Stein (2005) point out that care must be taken in interpreting longitudinal studies because they reflect survivors who are more likely to be better adjusted. Kemp (2004) reported on QOL in 1,000 people ageing with a disability, including SCI. The group with no disability had somewhat higher QOL scores. QOL in the group of people with SCI was unrelated to either the severity of the impairment or the degree of disability, with there being as many people with high QOL who had tetraplegia as paraplegia. Also there was a positive correlation between time since injury and QOL. Factors that correlated with high QOL were engagement in social, recreational, family and productive activities.

Albrecht and Devlieger (1999) refer to this apparent anomaly as a 'disability paradox'. They suggest that people with serious and persistent disabilities often report perceptions of personal health, well-being and life satisfaction that are different from their objective health status and disability. To develop an understanding of this paradox, a qualitative approach using a semi-structured interview with 153 people with disabilities (equal distribution of arthritis, SCI, cerebral palsy, multiple sclerosis, orthopaedic conditions, head injury, Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS), heart disease, eye/vision problems, chronic obstructive pulmonary disease, diabetes, chronic pain, addiction/mental illness) was undertaken with people being interviewed in their homes, community settings and shelters for the homeless between October 1995 and July 1997 in the Chicago metropolitan area. The results indicated that 54.3% of the respondents with moderate to serious disabilities reported having an excellent or good QOL.

Albrecht and Devlieger (1999) maintain that QOL is broader than the notion of health-related quality of life (HRQOL) which they suggest was developed as a result of major concerns in health care because of chronic illness, new technology, cost containment, interest in medical outcomes and a concern to humanise healthcare. They describe QOL as a holistic concept that transcends activities of daily living and disease categories because it directs attention to the more complete social, psychological and spiritual being. Albrecht and Devlieger (1999)

suggest the disability paradox results in a framework that summarises and organises the concepts, relationships and factors that persons with disabilities say influence their QOL for better or for worse. The central concept is establishing and maintaining a sense of balance between the body, mind and spirit and the individual's social context and environment. Those people who have a high QOL obtain an understanding of their condition, take control and introduce order and predictability in their lives. They learn what is possible, set goals, develop values that make sense of their disability, and search out resources to manage their lives better. They engage in social networks and give to and receive from others in a reciprocal relationship. These people re-create their social worlds in balance with the different types of 'social glue' that hold their lives together. Those who do not experience a high QOL do not have order and predictable worlds. Nor do they possess the knowledge, resources and social contacts that provide the connections necessary to reconstruct the balance and well-being in their lives. Often the low QOL is related to disabilities that produce fatigue, constant or unpredictable pain, and social environments that discourage them from becoming empowered to act as agents of their own lives.

Drum et al. (2008) suggest that contemporary perspectives on disability have helped explain this paradox with an emerging notion rejecting the idea that disability is equivalent to ill-health and instead make distinctions between "disability", "health" and "function". Drum et al. (2008) conclude that people with disabilities who might be expected to rate their overall health poorly (based on the number of unhealthy days experienced) instead rate their health more highly than do their non-disabled counterparts with a similar number of unhealthy days. This suggests that the relevant norms for self rating of health may differ between people with and without disabilities. They suggest that the findings parallel studies of 'elders' that have found that self-reported health does not necessarily match with medical assessments.

Kemp et al. (2004) consider that there were three important psychosocial issues associated with ageing with SCI: 1) how to maintain as high a QOL as possible while adjusting to age-related changes, 2) the problem of depression as people try to cope with these changes and losses, and 3) of the issue of caregiving, both within the family and in terms of service systems. Coping with age-related changes in disability has an impact on the development of depression and is arguably the most important psychological problem among people with SCI. Rates of depression, both moderate and major have been reported to be three to four times higher in people with SCI than in the non-disabled population (Krause et al., 2000).

Depression can have devastating effects with increased health problems, decline in functioning and shorter life expectancy.

Key studies on ageing with SCI and QOL

This section summarises specific research studies that have investigated QOL with persons ageing with SCI. There is a relationship between the time someone has lived with SCI, physical deterioration and development of secondary conditions and how these affect QOL ratings. With the wide range of interpretations of what QOL may mean, it has been difficult to write a comprehensive overview of QOL when reviewing these studies. As they are different in both context and the way they have investigated and evaluated QOL, they therefore have been addressed individually to help identify common themes and/or factors that may assist with gaining a better understanding of the implications of QOL when ageing with SCI.

Of the nine key QOL studies reviewed in the Table 3.1, five were longitudinal studies or part of longitudinal studies (Charlifue & Gerhart, 2004; Krause & Broderick, 2005; McColl et al., 2003; McColl et al., 2004; Whiteneck et al., 2007), two were cross-sectional studies (Liem et al., 2004; Putzke et al., 2003), one undertook a comparison across six countries (Geyh et al., 2012) and one reviewed 21 studies investigating subjective QOL (Sakakibara et al., 2012). All studies looked at QOL from both objective and subjective perspectives. The studies are presented in chronological order both in the table and in the text.

Table 3.1 Key quality of life studies involving people ageing with SCI

Study	Objective	Participant No.	Type	Assessment Tools
Putzke et al. (2003)	To determine the unique effects of age across a variety of outcome domains following SCI.	6132 individuals from the USA-based National Spinal Cord Injury Statistical Centre (NSCISC) geographically dispersed across USA.	Cross-sectional study. Objective & subjective.	Functional Independence Measure (FIM), Satisfaction With Life Scale (SWLS), SF-12, Craig Handicap Assessment & Reporting Technique (CHART).
McColl et al. (2003)	To qualify relationships among demographic factors, health and disability and QOL.	352 injured 20 years or more from USA, Britain and Canada.	Cross-sectional study using data from 1999. Part of a longitudinal study. Objective & subjective.	Current Problem Questionnaire (CPQ), & Life Satisfaction Index (LSI).
Liem et al. (2004)	To determine the frequency of need for help with ADLs; the frequency of medical complications; and association between medical, injury related, and socio-demographic factors and the need for	352 injured 20 years or more from USA, Britain and Canada.	Cross-sectional study using data from 1998-1999 from part of a longitudinal study.	Telephone interview to obtain information on recent medical history and current status.

	more ADLs among those ageing with SCI.			
McColl et al. (2004)	To identify differences in the ageing experiences of men and women with SCI.	134 (67 men & 67 women) injured 20 years or more from USA, Britain & Canada.	Part of a longitudinal study. Objective & subjective.	Perceived Stress Scale (PSS), CHART, Index of Psychological Well-being (IPWB), CPQ,& LSI.
Charlifue & Gerhart (2004)	To examine how stress, life satisfaction, depression, and psychological well-being relate to perceived QOL with longitudinal SCI.	189 injured 20 years or more from Britain.	Part of a longitudinal study. Objective & subjective.	Life Satisfaction Index (LSI-Z), IPWB, Center for Epidemiological Studies Depression Scale (CES-D) & PSS.
Krause & Broderick (2005)	To investigate the natural course of changes in activity patterns, health indicators, life satisfaction and adjustment.	In 1974 started with 256 respondents, 25 years later reduced to 95 respondents. Preliminary data was collected from Midwestern USA. Follow-up data collected from large south-eastern USA rehab hospital.	25 year longitudinal study. Objective & subjective.	Life Situation Questionnaire (LSQ).
Whiteneck et al. (2007)	QOL and health in the last years after SCI.	QOL: N=377 Health: N=373 USA based.	Part of a longitudinal study. Objective & subjective.	CHART, SWLS, Medical History and Current Status Questionnaire (MHCSQ), Brief Pain Inventory (BPI),IPWB, LSI-Z,CES-D, PSS, LSQ-R, Functional Assessment of Chronic Illness Therapies -- Spiritual (FACIT-SP), Interpersonal Support Evaluation List (ISEL), Personal Attendant Care Questionnaire (PACQ), & Health Services Access Utilisation and Satisfaction (HSAUS).
Geyh et al. (2012)	QOL after SCI: a comparison across six countries.	243 people with SCI from Australia, Brazil, Canada, Israel, South Africa and the USA.	Objective & subjective.	Demographic information and 5 items from the WHO Quality-of-life Assessment - BREF (WHOQOL-BREF).
Sakakibara et al. (2012)	To identify changes in subjective QOL as one ages with a SCI.	Electronic databases were searched for studies reporting on age-related QOL changes over time.	Subjective.	A systematic literature review with 21 studies being selected for review.

Putzke et al. (2003) suggested that cross-sectional and longitudinal studies on SCI people ageing have concentrated primarily on the physical (increased risk of health complications, re-hospitalisation, nursing home placement, pain, lower self-reported health status) and functional (reduced sitting tolerance, mobility, physical independence, self-care ability) quality of life domains. The authors suggest that previous research has been characterised by at least one of three methodological limitations, 1) assessment of a limited range of QOL domains, 2) small sample size among those aged over 65 years, and 3) limited control for other demographic and medical characteristics that may influence outcomes that would help tease apart the specific effects of age versus a variety of other factors (Putzke et al., 2003).

Acknowledging the limitations of a cross-sectional study, Putzke and colleagues found significant linear decline with increasing age for functional independence, overall life satisfaction, and perceived physical health and handicap, particularly in the areas of physical independence, mobility, occupational functioning, and social integration. The proportion of individuals reporting pain in daily activities showed significant linear increase with age. Self-reported mental health and economic functioning were relatively unrelated to age. Although the results tended to support a consistent age-related decline on most outcome measures, regression analysis controlling for numerous demographic and medical characteristics indicated that the unique variance that could be specifically attributed to age was relatively low. The authors suggest that research should concentrate on the extent to which small specific effects of age across outcome domains can be attributed to age-related changes in outcome measurement. It is unclear whether measures traditionally designed for the younger spinal-cord population accurately capture the functional concerns of older people with SCI.

McColl et al. (2003) specifically looked at SCI and QOL using a sample of people aged at least 40 years and older who had incurred SCI at least 20 years previously and who had been between the ages of 15 and 55 at the time of injury. Cross-sectional analysis was undertaken using data collected in 1999 from their longitudinal study. They concluded that higher QOL was related to fewer health and disability-related problems. Older participants were found to have more health problems, and those with higher lesions were found to have more disability related problems. Lower QOL was related to older age and the perception of accelerated ageing. The perception of ageing more quickly was prevalent among those with more health problems and more fatigue. The authors suggest that there are basically two groups of long-term survivors: those who experience relatively few secondary complications and age with

some degree of ease, and those who experience multiple health problems combined with having a higher lesion and more disability-related problems.

McColl et al. (2003) found that the longer someone lived with their disability the less their perception that the disability was an issue. The authors suggest that the longer someone lives with SCI the more they discover that the impact of ageing affects not only them but also able bodied contemporaries therefore with increased ageing there are potentially fewer negative comparisons to be drawn. An interesting observation was that fatigue was greatest amongst those who were younger and had a shorter duration of disability. When looked at closely, the group between the ages of 40 to 65 years who commented on being fatigued, were working, with fatigue related to the number of hours worked. As a person ages they learn to live within their capabilities which included accommodating the limitations of their disability. However, McColl and colleagues commented that many persons with SCI did not anticipate reaching retirement age therefore had not appropriately planned for retirement, especially financial support.

Liem et al. (2004) undertook a cross-sectional secondary analysis of a dataset obtained from surveying individuals with SCI living in the community. The 352 participants who were at least 20 years post-injury were part of the McColl et al. (2003) longitudinal research study. The objectives of the study were to investigate the amount of help needed with activities of daily living (ADL), the frequency of medical complications, and the association between medical, injury related, and socio-demographic factors and the need for more help with ADLs among those ageing with SCI.

In regard to the frequency of needing more help with ADLs, 32% acknowledged that they had needed more help to perform ADLs within the last three years. Transfers were the most problematic activity (34.6%) followed by housework (25.4%). Those needing more help with ADLs were significantly older and had lived longer with SCI than those not needing more help. Of interest was that the level and completeness of injury were not related to needing more help with ADLs. Over the previous three years 84.7% of interviewees reported at least one medical diagnosis, hospital admission, or operative procedure. The most common reported medical problems were skin problems (44.3%), gastrointestinal problems (23.6%) and genitourinary problems (21.3%). When asked about specific complications of SCI, bowel problems were the most commonly cited, including constipation (47.9%) and diarrhoea or bowel accidents (41.8%). Lower extremity fractures (16.5%) were relatively frequent, consistent with the consequence of osteoporosis due to the lack of weight-bearing in SCI.

Also noted were neuro-musculoskeletal problems (14.2%) involving complications such as stroke, tethering of the spinal cord and compressive mononeuropathies and consequences such as spasticity (14.2%). Upper extremity joint problems (11.6%) were also common.

When looking at the relationship between medical factors and the need for more help with ADLs, the researchers found that there was a 97% increase in the need for ADLs for people incurring constipation, and a 76% increase for people incurring pressure ulcers, during the past three-year time period. Women were found to have a 96% increased odds of needing more help with ADLs compared to men. Liem and colleagues suggest medically, woman may require more help with ADLs because of musculoskeletal problems such as the occurrence of upper extremity joint and ligamentous problems. This could be due to biomechanical differences between women and men. Finally, there was a 42% increase in the odds of needing more help per decade of living with SCI. Of these four factors, constipation and pressure ulcers are potentially preventable through lifestyle modification, medication or rehabilitation intervention. Impact of gender and the number of years post-injury, although not modifiable, are important factors in any risk assessment. Liem et al. (2004) go on to suggest that lifestyle factors play a large role in the development of these complications and compound spinal cord and age-related changes.

Using participants from the longitudinal international study on ageing with SCI, McColl et al. (2004) compared the differences in ageing experiences of 67 men and 67 women who had been injured for at least 20 years. They were matched on age, country of origin (England, Canada and the USA) and duration of disability. Participants had an average age of 57 years and average disability duration of 33 years. Due to the small sample number and a desire to detect all possible differences for further exploration, a liberal value of P less than 0.10 was used as a threshold for defining a significant difference. Significantly more men than women reported health problems, especially in relation to the incidence of diabetes (which is similar to rates in the general population). Women reported significantly more transportation problems and it was suggested this may be due to men being more likely to drive their own cars and be more familiar with the technology to permit them to do so. Women were more likely than men to report that they were ageing more quickly, whereas men were more likely to perceive that they were ageing with more difficulty or having more complications. Women reported more pain affecting the back, hands, and tasks associated with ADLs. Regarding marital status, more men were married, separated or divorced, and more women were single

or widowed. The researchers reported that this is a common finding in studies not only in SCI but in disability in general.

Although there was no significant difference in the reported incidence of pressure ulcers women had three times (16 days vs. 5 days) more disability days associated with skin breakdown than men. It was suggested women may experience more severe skin lesions (McColl et al., 2004). Alternately the men in the sample were more likely to be married (50% vs. 40%) and may have more attention given to the condition of their skin by informal caregivers. Thus they are more likely to find a skin lesion in its early stage before it becomes difficult to treat. Men spent, on average, twice as many hours working as did women and women spent, on average, more than twice as many hours in homemaking tasks. There were no significant differences between the amount of time men and women spent out of bed each day (13.9 hrs vs. 13.5 hrs), or the number of days spent out of the house each week (4.7 days vs. 4.1 days). Women reported spending more time in recreation, self-care and volunteering. On average they were able to account for eight more hours a week than men spent in productive activities. There were no differences between men and women in overall QOL, life satisfaction, psychological well-being or perceived stress (McColl et al., 2004).

Charlifue and Gerhart (2004) examined stress, life satisfaction, depression and psychological well-being related to perceived QOL among the 189 people with long standing SCI (injured a minimum of 20 years, evaluated at 3 year intervals from 1990 to 1999). In 1999 the group had a mean age of 59.4 years and mean time since injury of 36 years, 85.7% were male, and 32.3% were tetraplegic, 48.1% paraplegic, and 19.6% incomplete. Over the time period there were significant relationships between perceived QOL and perceived well-being, depressive symptoms and life satisfaction. The Life Satisfaction Index (a 13-item self-reported assessment of morale or life satisfaction) scores were significantly correlated with perceived QOL over the three time points. Perceived well-being was correlated at only one time point while stress and depression were not significantly correlated. The repeated measures analysis failed to yield significant results with the exception of the Life Satisfaction Index scores which differed significantly by age group and duration of injury, but no clear trends over time were apparent.

The authors however do suggest that many significant changes were noted when looking at the earliest time point (1990) for the outcome measure and the change to the latest time point (1999). Being male, older, longer injured, and having complete paraplegia were related to worse outcomes associated with stress and depression. The perception of good health

remained relatively stable over time with approximately 79% of participants indicating they felt generally healthy at each time period. Charlifue and Gerhart (2004) concluded that individuals with SCI of long duration (12 years) have a perception of QOL that remains relatively stable.

The authors point out the following limitations of the study. First, the 1999 sample consisted of those participants who had wished to continue their participation. It is unknown whether those who chose not to continue may have had a poorer perceived QOL or poorer outcomes in the psychosocial areas. Second, the subjects in 1999 were clearly among the longer living SCI survivors and therefore their experience cannot be generalised to the majority of persons with SCI. These participants were injured at a time when surviving the initial injury and its many complications were not a foregone conclusion. Third, one key area related to perceived QOL (social support), was not assessed in the earlier phases of the study. Fourth, although the study further confirms that people who live with long-term SCI with all its complications, frustrations and limitations, see themselves as having a higher QOL, it still fails to address why this so. The authors indicated that other researchers have suggested that people with disabilities and older populations themselves alter the criteria that serve as a yardstick against which they measure the quality of their lives. They may devalue unattainable goals while increasing the value of those things which they can succeed with in order to enhance their self-esteem, happiness, and their QOL.

A longitudinal study by Krause and Broderick (2005) investigated changes in activity patterns, health indicators, life satisfaction and adjustment over 25 years post-injury among participants from the USA. In 1974 there were initially 256 respondents (85% response rate) aged at least 18 years and minimum of two years post-injury. Twenty-five years later there were 95 (37%) respondents; 36 (14%) refused to participate; 77 (30%) were deceased; and 46 (18%) could not be located. The mean age of the 95 respondents was 53.8 years, the average time since injury was 32.2 years, 83% were males and 70.5% were tetraplegic. The nature of the changes over the 25 years period reflected a mixture of enhancement and decline.

Employment clearly improved over 25 years (44% vs. 52%), as did satisfaction and greater tenure at current job (3.6 years vs. 17.7 years). The number of medical treatments increased between the two measurement waves while the number of days hospitalised decreased. There were no significant differences in the number of hospitalisations. Four of the six life satisfaction variables significantly changed over the 25 years period; satisfaction with employment increased whereas satisfaction with health, social life, and sex life decreased.

Attrition analysis indicated respondents that were both younger at the time of the 1974 data collection and had lived fewer years post-injury and were more likely to have cervical injuries than non-respondents. Respondents, who reported more years of education and greater satisfaction with their health, predicted that their overall adjustment would be better in five years from 1974 when the data was collected.

Those who did not respond tended to be individuals who were older, older at time of injury, had been injured for a longer period of time, had the least active pattern of participation, had the least satisfaction with their health and had poorer projected adjustment, and obviously were more likely to have died or chosen to leave the study over the 25 year period.

Krause and Broderick suggested that the cohort of participants who responded may have the greatest abilities to adapt to the changing demands imposed by SCI and they may not be representative of the broad spectrum of individuals who acquired SCI. They point out that medical professionals need to be aware that the decline in health and increased likelihood of medical treatment and perhaps even lengthy hospitalisations amongst those ageing with SCI represent the “natural course of ageing” and clients may benefit from attention to these issues early on.

Limitations of their study include: 1) the life skills questionnaire was limited in both breadth of content coverage and adequacy and measurement of content areas; measures of recent medical history and activity patterns were limited by the group frequencies; 2) although there was a balance of participants based on gender, there were no racial or ethnic minorities; and 3) the authors chose not to correct for multiple statistical tests, which inflated the likelihood of rejecting the null hypothesis when it is indeed correct. Lastly attrition due to all causes, most commonly mortality was relatively substantial over the 25 years period, even though the effective response rate was extremely high (Krause & Broderick, 2005).

Whiteneck et al. (2007) investigated the question of what people with SCI could likely expect in terms of QOL and health as they approached the end of their life using longitudinal data from the American-based multi-centred Model Spinal Cord Injury Systems (MSCIS) Collaborative Aging Study (Charlifue, 2007). After three 5-year rounds of data collection from 1990 to 2005, the 15 year longitudinal study found only one in four people with a SCI reported poor or fair QOL and only one in 10 reported not being generally healthy. Significant risk factors for poor or fair QOL were having increasing bowel problems, low social integration, low community mobility, increasing skin problems, and increasing joint pain.

Each additional year post injury reduced the likelihood of poor or fair QOL. Significant factors associated with not generally being healthy were having increased fatigue, low social integration, incomplete injury, and low community mobility. The only significant risk factors for mortality were age at injury and low community mobility. Each year of age and each additional year post injury increased the likelihood of mortality. These findings would indicate worsening medical conditions, such as bowel and skin problems, joint pain and fatigue as well as reduced participation in society had a direct impact on perceived QOL and health. The authors suggest this gives good reason to develop ways to identify the development of such secondary conditions early to enable intervention and treatment.

The international study by Geyh et al. (2012) examined the QOL of 243 people with SCI across six countries (Australia, Brazil, Canada, Israel, South Africa and the USA) controlling for socio-demographic and lesion related sample characteristics, using a cross culturally valid assessment tool, the World Health Organization Quality of Life Assessment –WHOQOL - BREF. The sample mean age was 41.4 years; mean time since injury 11.6 years; 50% paraplegic and 79.4% male. QOL was found to be statistically different with the QOL being the highest in the USA and lowest in Brazil. Participants who had lived with a SCI longer and were in paid employment reported a significantly higher QOL irrespective of country, socio-demographic, lesion characteristics and education.

The researchers concluded that employment and the broader concept of participation contributed to people's QOL. They suggest that employment brings financial status, self realisation, self-esteem, health and better overall social integration. Although the time since injury ranged from one month to 50 years, with it being statistically controlled for in the regression model, it was found to be positively related to QOL. There were no associations between lesion related characteristics, socio-demographic characteristics, age, gender, relationship status and education. Limitations identified by the authors included the recognition that the WHOQOL-BREF used only five items which meant the amount of variance in the QOL that could be explained was relatively small. Also information was not obtained about other domains of life with which a person with SCI might be more or less satisfied. The sample of countries was relatively small and did not cover all regions within a country's cultural variation. They concluded that the generalisability of the findings was limited.

Sakakibara et al. (2012) undertook a systematic review of the literature focusing on the influence of ageing on subjective QOL after SCI. Inclusion criteria were that the articles were

published in English, in a peer reviewed journal between 1980 and September 2011, had a sample that comprised at least half adult participants with a traumatic SCI and evaluated the effects of ageing on subjective QOL by longitudinal or prospective research designs. Studies evaluating HRQOL were excluded; but the subjective data from studies using a combined health-related subject of QOL measure were included. After examining 246 possible papers 21 (USA 14, Great Britain 3, the Netherlands 2, Canada 1 and Sweden 1) were selected for review. Six QOL domains were looked at: living arrangements, employment, finances, social life, sex life, and general health. The sample sizes ranged from 17 to 6451 subjects; the mean age ranged from 18.1 to 51.9 years; and the mean number of years post injury (YPI) ranged from 0.9 to 26.8 years. A consistent finding was that, regardless of chronological age, individuals with relatively new SCI (≤ 5 YPI) have the potential to improve their overall QOL or various QOL domains.

Age at onset of SCI did not appear to preclude high QOL. However, it was noted that within the various age categories there were likely to be differing age related factors that might potentially influence QOL. It was also further noted that among individuals with advanced YPI, overall QOL was consistently reported as good or excellent over time, although there was variations within the different QOL domains. The authors commented that the quality of evidence being used to draw the conclusions were relatively low and suggest that more research with greater methodological and measurement rigour is required to corroborate the findings and conclusions of the review.

3.7 Environmental and community factors

This section specifically looks at research that illustrates how the external environment and living in the community influences people ageing with SCI. The foundation for environmental improvements began with the development of the theoretical social models of disability (Oliver, 1990, 2013; Putnam, 2002) and the United Nations *Convention on the Rights of Persons with Disabilities* (World Health Organization, 2011b) adopted in 2006 which were discussed in Chapter 1. The link between the social model of disability and disabled people becoming politically active was important in influencing societal changes that resulted in the breakdown of social barriers and provision of access to public transport, buildings and employment. How this came about and its impact is discussed in Chapter 2. Such political activism by disabled people influenced legislative change in many countries, ensuring that

their communities became more inclusive and catered better for disabilities with suitable building codes, employment and human rights legislation (Beatson, 2004).

Specific improvements for wheelchair users have included accessible footpath curve ramps, ramps and lifts into buildings, wheelchair friendly public transport and disabled/wheelchair accessible toilets. People ageing with SCI are able to actively participate in community activities including working and socialising, which has enabled a more inclusive society. The following articles specifically look at environmental factors and living in the community and how they have influenced people who are ageing with SCI.

The Krause and Sternberg (1997) study used a time sequential design to isolate the impact of environmental changes on life adjustment after SCI between 1985 and 1994. In addition, chronological age and time since injury was evaluated. There was no overlap between the two participating samples taken from outpatient files of two large USA mid-western hospitals. Inclusion criteria consisted of participants having traumatic onset of SCI, a minimum of two years since injury, and being at least 18 years of age. The Life Situation Questionnaire that evaluated education and employment, activities and participation, medical treatments, adjustment and life satisfaction was sent to both samples in 1985 and 1994. Of the 266 potential participants in the 1985 sample, 193 (73%) returned usable questionnaires. In the 1994 sample, 201 (81%) people out of 247 returned usable questionnaires. No differences were identified between the two samples according to gender (male 80%, female 20%), severity of injury (cervical 56%, other 44%), or completeness of injury (complete 54%, incomplete 46%). Participants in the 1994 sample were older at the time of injury (29.2 years vs. 26.0 years), had a greater number of years since injury (11.2 years vs. 9.3 years), and a higher number of years of education (14.3 years vs. 13.6 years). Ageing appeared to be associated with a less active and generally less rewarding lifestyle, with participants sitting for shorter periods of time and less frequent social outings from their homes. They were also less satisfied with several aspects of life but did not report greater problems with boredom, loneliness or depression. Age was also associated with an increase in subjective chronic health problems, despite there being no relationship between age and the number of doctor visits or hospitalisations. Not all outcomes were negatively correlated with age, with older participants more satisfied with their living arrangements, finances, and reporting fewer problems with income and alcohol or drug abuse.

The authors suggest that age appears to be related to a more sedentary lifestyle in which activities within the home take on a more central role. They suggest this may reflect a normal

ageing process with physical limitations due to SCI placing an added burden on the oldest individuals, with them being less adaptable to the lifestyle changes necessitated by SCI. In contrast with chronological age, increasing time since injury was associated with a more satisfying lifestyle, less emotional distress and fewer hospitalisations. Satisfaction with employment, life opportunities and emotional adjustment were most strongly related to an increase in time since injury. Krause and Sternberg suggest this confirms findings that adapting to SCI is a gradual process, with people learning a variety of successful adaptive strategies.

There was a consistent pattern of differences between the two time-points (1985 vs. 1994) such as a significant decline in life satisfaction and an increase in problems. The authors suggest that it is particularly interesting that the 1994 sample reported more problems, with lack of accessibility and negative societal attitude towards the disabled. This suggests that persons in 1994 found their environment more problematic compared to those in 1985. In contrast, negative changes in subjective areas showed no differences in social or vocational activity patterns. Although the study was not designed to answer why environmental changes would contribute to the diminished well-being among people with SCI, the authors speculate that the passing of the Americans with Disabilities Act in 1990 may have raised unrealistic expectations. There had been a large amount of media attention and public discussion focused on sweeping changes to the nation's health care system, including potential cutbacks, and the current findings may have reflected an actual decline in health care services or social programmes provided to the participants.

Whiteneck et al. (2004) investigated how environmental barriers reported by 2762 people with SCI (78% male, 41% paraplegic, 38% tetraplegic, 36% injured 15 years or longer) affected activity, participation and life satisfaction. The sample was composed of people with SCI who met the criteria for participation in the American-based multi-centred MSCIS programme. Twenty percent of participants reported there were no barriers that interfered with what they wanted to do. The other 80% ranked barriers from being minor to large problems encountered daily. The five environmental barriers, in order of importance, were: natural environment, transportation, need for help in the home, availability of health care, and government policies. Using the Craig Hospital Inventory of Environmental Factors (CHIEF), an instrument designed to quantify the frequency, magnitude and overall impact of perceived environmental barriers, the authors found significant differences in age at injury (oldest and youngest age groups reporting the most barriers), women reporting more barriers, unmarried

people reporting more barriers, but people with more years post injury reporting fewer barriers. Whiteneck et al. (2004) concluded that environmental factors, participation, YPI, and gender were the only significant predictors of life satisfaction. They suggest that the study supports previous research findings that life satisfaction is more strongly related to participation than to impairment or activity limitations. They raise some very interesting questions by suggesting that when people are faced with barriers they overcome them but at the same time experience reduced life satisfaction. They go on to suggest that maybe life satisfaction is more closely related to perceived barriers than objective environmental assessments and that ways should be investigated to objectively assess environmental factors independent from the person with the disability.

Carpenter et al. (2007) explored the relationship between participation and life satisfaction in the community. The sample of 357 people recruited through the Canada-based British Columbia Paraplegic Association had a mean age of 46 years, mean time since injury of 13 years, 48% lived in a spousal relationship, and 60% were male. There was general overall satisfaction with access to public buildings. Respondents recognised the importance of physical activity, with 75% undertaking some form of physical exercise. Those living alone were less satisfied with the support they received than those living with others. In general, respondents were happy and satisfied with life. Satisfaction with transportation was significantly related to having ownership of one's own vehicle. Age was not associated with life satisfaction or happiness whereas duration of SCI showed a modest positive association with life satisfaction but not with happiness. Satisfaction with social support was significantly associated with life satisfaction and happiness. The higher the income, the greater the life satisfaction but income did not affect happiness. The authors concluded that life satisfaction is more strongly related to community participation than impairment and activity limitations.

3.8 Conclusions

This section concentrates on three topics arising from this review which directly relate to the research undertaken in the doctoral thesis. These topics will be expanded on further in Chapter 8, the discussion.

The changing demographics of people with SCI

With the world-wide population getting older and the number of people 65 years and older expected to approximately double by 2050 it will have a corresponding impact on the demographic makeup of people who incur SCI. With the general population ageing the

number of previously non-disabled adults acquiring SCI impairments in later life will also increase. It is likely that there will be a convergence of disability status and experiences in later life between older people who sustained SCI when younger or middle aged and those who acquire them when older. This will result in more diversity amongst older age groups.

The life expectancy of people with SCI has improved to the point that a person with SCI can expect to live to 85% to 90% of an able-bodied person's equivalent age. Most studies on incidence rates of SCI indicate a bimodal distribution with the first peak being young adults in the age group between 15 and 29 years, with the SCI mainly caused by MVA and the second peak being older adults over the age of 60 years of age with the injury being mainly caused by falls (Burt, 2004; DeVivo, 2012; Ho et al., 2007; Jackson et al., 2004; van den Berg et al., 2010; Wyndaele & Wyndaele, 2006). With an increasing older population, it will require specialised SCI acute and post-acute medical and rehabilitation services to respond appropriately. Such services will need to cater for an increasing number of older people sustaining SCI and the associated complications of having a SCI when older. At the same time, there will be an increasing number of people who sustained their SCI when younger or middle aged who will be ageing and, in many cases, incurring physical deterioration with the development of secondary complications which will impact on their health and QOL.

Accelerated ageing or diversity in ageing?

Clinicians and researchers working in the field of ageing with SCI have referred to people with SCI as 'prematurely ageing' or having 'accelerated ageing' similar to that described among polio survivors and persons with other chronic disabling conditions. This concept is based on biological deterioration of the body due to either the impact of SCI or living with SCI (or both) speeding up the biological deterioration. A wide range of factors can affect this biological decline such as neurological level, extent and duration of injury, age at time of injury, weight, premorbid health history, medical comorbidity, gender, ethnicity, success of rehabilitation at time of injury, alongside a complex interaction of genetic factors, lifestyle, adaption to stress and social roles, alterations in living situation and family structure, and potential depletion of social and economic resources (Adkins, 2004; Capoor & Stein, 2005; Groah et al., 2012; Kemp et al., 2004). Such biological deterioration also happens in ageing able-bodied people to differing degrees.

The ageing population will become more diverse in terms of disability, physical and social abilities of individuals whether disabled or able-bodied. There is evidence from longitudinal

research studies that people who incur their SCI when young adults or middle aged go through a period of relative stability of between 20 to 25 YPI before starting to develop a variety of possible secondary complications. How these secondary complications are identified and managed by the individual and medical specialists is important in how persons with SCI manage their lives from that time on. A crucial factor in this scenario is that the younger a person originally sustains their SCI, the earlier in their life-span they are likely to encounter the development of secondary complications.

Rather than people with SCI being labelled as ‘prematurely’ ageing it could be suggested that they are part of a wide range of people with disabilities and able-bodied people who are, in general terms, ageing in a diverse fashion. This diversity is part of the human condition and our general life-span whereby we all face physical, functional and environmental changes as we age. As people age regardless of whether they are able-bodied, have SCI or another type of disability, there is a need to constantly re-evaluate and adjust as health, environment and social circumstances change. There will be an increasing number of people ageing with SCI that are currently consumers of disability related services. However, at some point, they will also become consumers of age-related services. How this new cohort of people ageing with SCI, with their associated complex secondary conditions, will affect services for the older age groups is currently unclear.

Quality of life

Evaluating QOL depends on whether it is from an objective or subjective perspective. The World Health Organization definition on QOL leans towards being more subjective, stating that it is “an individual's perception of their own position in life in the context of the culture and the systems in which they live” (Wood-Dauphinee et al., 2002).

In studies on ageing with SCI and QOL there appears to be a positive correlation between the YPI and a higher perception of QOL compared to later onset of SCI which is associated with lower QOL. Higher QOL is related to less health and disability related problems than to active participation in the community, especially employment, whereas lower QOL is related to gender (female), YPI, multiple health problems combined with having a higher lesion and more disability related problems. It would seem that the key ingredients for a good perception of QOL are participating in enjoyable activities and a feeling of contributing to society to fulfil one's potential. Good social support systems and coping skills are crucial to managing age-related changes to function.

Many studies suggest that the longer someone lives with SCI the more likely they are to report overall QOL as good or excellent. They also discover that ageing affects not only them but also able-bodied contemporaries, and therefore their SCI is seen as less of an issue. Charlifue and Gerhart (2004) suggest that people with disabilities and older people alter the criteria that serve as yardsticks against which they measure QOL. They devalue unattainable goals while increasing the value of those things they can achieve to enhance their self-esteem, happiness and their QOL. These are all relevant points that go some way to explaining why subjective QOL is often rated relatively high by ageing SCI people, even including high level tetraplegics.

The concept called the ‘disability paradox’, proposed by Abrechrt and Devlieger (1999), attempts to explain this anomaly by suggesting that people with disabilities who rate QOL as high, or very high, obtain an understanding of their condition/disability by taking control and introducing order and predictability in their lives. They learn what is possible, set goals, develop values that make sense of their disability, and search out resources to manage their lives better within their environment. They engage in social networks and give to and receive from others in a reciprocal relationship. This rationale is very similar to the concepts of the independent living put forward by Gerben de Jong and promoted by Professor Alan Clarke that were described in Chapter 2 (Cassidy et al., 2004; DeJong, 1979). Such concepts explain not only why subjective QOL can be rated positively but also why many ageing people with SCI cope well with the development of secondary conditions associated with ageing and continue to lead active and full lives.

Chapter 4: Methodology and overview of methods

4.1 Introduction

Outlined in this chapter are the rationale and discussion of the mixed methods approach adopted for this research, an approach which combines both qualitative and quantitative research techniques. Also presented is a brief overview of the methods employed. A detailed description of the methods for the qualitative, database development, and quantitative research components is presented in Chapters 5, 6 and 7 respectively. The findings from each piece of research are brought together and discussed in Chapter 8.

4.2 Mixed Methods Approach

Mixed methods research had been defined as “integrating quantitative and qualitative data collection and analysis in a single study or programme of inquiry when used in combination, both quantitative and qualitative data yield a more complete analysis, and they complement each other” (Creswell et al., 2004). Creswell (2009) added that mixed methods involve philosophical assumptions, the use of qualitative and quantitative approaches, and the mixing of both approaches in a study. Johnson and Onwuegbuzie (2004, p. 17) define mixed methods as research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language into a single study.

A strength of mixed methods design is that the breadth of findings can bring value to the research process itself by highlighting the particular shortcomings in each of the methods used and compensating for them. When the findings are contradictory, the mixed methods approach can reveal research assumptions that would not otherwise have been known or the constraints and biases in measurement and interpretation. However, what makes this design most attractive to health researchers is its pragmatism. Johnson and Onwuegbuzie (2004, p.16) state they do not aim to solve the metaphysical, epistemological, axiological and methodological differences between the purist positions. Instead they suggest mixed methods research should be used as a method and philosophy that attempt to fit together the insights provided by qualitative and quantitative research into a workable solution. The authors refer to Hoshmand (2003) to suggest that pragmatism also helps to shed light on how research approaches can be mixed beneficially by being mixed in ways that can offer the best opportunities for answering important research questions. That is, its usefulness in the clinical

or applied setting for collecting comprehensive information about a phenomenon that can then guide decisions about practice (Giddings & Grant, 2006). One data source or line of enquiry may not be sufficient and using mixed methods can make up for the respective weaknesses of both qualitative and quantitative research. One way it does this is by honouring the voices of research participants in a way that quantitative research rarely can (Creswell & Plano Clark, 2011).

While having salient strengths, mixed methods research also poses some serious challenges. In particular, it is necessary for the researcher to acquire sufficient skills in both qualitative and quantitative research to do them both well; the research often takes longer and requires more resources and a commitment to make the case to readers that mixed methods research is legitimate and an appropriate form of inquiry. Inevitably, and unfortunately, some mixed methods studies yield weak qualitative and quantitative findings (Creswell, 2009).

Quantitative methods and the positivist paradigm were the dominant and relatively unquestioned method of research in the first half of the 20th century (Tashakkori & Teddlie, 2003). Most criticism of mixed methodology appears to come from qualitative researchers concerned that it privileges a post-positivist framework (Giddings & Grant, 2007). A core fundamental positivist assumption is that of determinism; the belief that effects have a determinable cause and actions have predictable outcomes. Post-positivists maintain this assumption in a modified form, assuming a direction of cause and effect. They perceive outcomes as the result of a complex array of causative factors that interact with each other. Mixed methods researchers are not always aware of the post-positivist underpinning of these studies (Giddings & Grant, 2006). Specifically, Giddings and Grant (2007) are sceptical that mixed methods approaches will produce the best of both worlds and call it a "cover" for the ongoing hegemony of positivism.

The term *mixing* has been labelled inappropriate for mixed methods research because qualitative and quantitative components are not really mixed; rather they are blended, meshed, combined (Bergman, 2011). However, Bergman (2011, p. 272) argues that, until there is good reason to abandon the now well established term "*mixed*", it should continue to be used. Moreover, he asserts that a type of research design will emerge where the line of demarcation between qualitative and quantitative components is no longer clearly identifiable.

Decisions on mixed methods research design require consideration of two important components: (i) the rationale for the use of mixed methods; and, (ii) the sequencing of

particular methods. Johnson and Onwuegbuzie (2004, p. 22) state that there are five rationales associated with mixed methods research design. These include:

1. triangulation - seeking convergence and collaboration of results from different methods and designs studying the same phenomenon;
2. complementarity - seeking elaboration, enhancement, illustration and clarification of results from one method with results from another method;
3. initiation - discovering paradoxes and contradictions that lead to a reframing of the research question;
4. development - using the findings of one method to help inform the other method; and
5. expansion - seeking to expand the breadth and range of research by using different methods for different enquiry components.

Cresswell (2009, p. 214) similarly describes the designs summarized in Figure 4.1 as being either sequential or concurrent in design. Sequential mixed methods are those that seek to elaborate and expand on the findings of one method (qualitative or quantitative) with another (qualitative or quantitative). All sequential designs share similar methodological strengths and weaknesses such as the substantial length of time it can take to complete data collection over two separate phases. Also the researcher has to make some key decisions about which findings from the initial phase will be focused on in the subsequent phase. Concurrent mixed methods are those which converge or merge quantitative and qualitative data in order to provide a comprehensive analysis of the problem. The research questions are the driving force behind the methodological choices, such as defining the problem, identifying the design and data sources, analysing, interpreting and reporting results. The choice of a concurrent model, whether it is a triangulation, embedded design or transformative, is made to facilitate this perspective (Cresswell 2009).

		Time Order Decision	
		Concurrent	Sequential
Paradigm Emphasis Decision	Equal Status	QUAL + QUAN	QUAL > QUAN QUAN > QUAL
	Dominant Status	QUAL + quan QUAN + qual	QUAL > quan qual > QUAN QUAN > qual Quan > QUAL

Note: “qual” = qualitative, “quan” = quantitative, “+” means concurrent, “>” stands for sequential, Capital letters denote high priority or weight, lower case denote lower priority or weight

Figure 4.1 Mixed-methods design matrix with mixed-methods design shown in the four cells.

Based on Johnson and Onwuegbuzie (2004)

4.3 Qualitative Research Approach

Qualitative research plays an important part in the mixed methods approach. It is a means of exploring and understanding the meaning individuals or groups ascribe to a social or human problem. The research process involves emerging questions and procedures, data typically collected in the participants’ setting, data analysis inductively building from the particulars to general themes, and the researcher making interpretations of the meaning of the data. The final written report has a flexible structure (Carter & Henderson, 2005; Creswell, 2009). Castro et al. (2010, p. 343) summarise the strengths of the *qualitative* approach as being (a) the capacity for generating rich detailed accounts of human experiences (emotions, beliefs, and behaviours), and (b) narrative accounts that are examined within the original context in which observations or recordings occur. The qualitative approach affords an in-depth analysis of complex human, family and social systems, and cultural experiences in a manner that cannot be fully captured with measurement scales and multivariate models (Plano Clark et al., 2008).

Castro et al. (2010) suggest that the limitations of the qualitative approach include difficulties in the reliable integration of information across observations or cases and difficulties in

assessing links and associations that occur between observations, cases, or constructs. Also qualitative research methods often lack well-defined prescriptive procedures (Morse, 1994) thus limiting the capacity for drawing definitive conclusions, an important aspect of scientific research. Purely qualitative studies have been challenged for their small or unrepresentative samples, and thus their limited capacity to produce generalisable findings. Although, some qualitative analysts have argued that the canons of scientific research — generalisability, replication, reliability, and validity are not relevant for qualitative research (Denzin & Lincoln, 1994).

In regards to the semi-structured interview process that was undertaken in Phase 1 of this research project, it contributes to the pragmatic approach identified earlier by Johnson and Onwuegbuzie (2004) whereby the choice of method contributes to a flexible approach to seeking relevant information. Particularly the interaction between the interviewer and the participants allowed the identification of descriptive views and opinions based on loosely structured questions. This enabled unique, rich information to flow about people's individual journeys of coping and adjusting to their SCI in what was a “generation of pathfinders” that challenged society's perception of disabled people and their roles within society. The process of summarising the information obtained involved using multiple stages of data refinement into categories of information which were then refined into general themes that identified key similarities and differences in the information.

4.4 Quantitative Research Approach

Cresswell (2009) describes quantitative research as a means of testing objective theories by examining the relationships among variables. These variables, in turn, can be measured, typically using well-designed instruments, so that the numbered data can be analysed using statistical procedures. The final written report has a set structure consisting of introduction, literature and theory, methods, results and discussion (Creswell, 2009). Castro, Kellison et al. (2010, p. 343) suggest that the strengths of *quantitative* approaches include (a) accurate operationalisation and measurement of a specific construct, (b) the capacity to conduct group comparisons, (c) the capacity to examine the strength of association between variables of interest, and (d) the capacity for model specification and the testing of research hypotheses.

One of the major limitations is that measurement detaches information from its original ecological “real world” context, in a way that has been referred to as decontextualisation (Castro et al., 2010). Polit and Beck (2010) point out that the identification of a population is

a group of people that have common, defined characteristics, about whom the study results are relevant. The goal is to select a sample that is representative of the population. The best strategy for achieving a representative sample is to use probability (random) methods of sampling. Like most models, this generalisability model is an *ideal* - a goal to be achieved, rather than an accurate depiction of what transpires in real world research. It is more likely there is an explicit accessible population, that is, a group to which the researchers have access and from which participants are sampled. Even accessible populations, which are linked to hypothetical target populations in a diffuse and often unarticulated way, frequently are ill-defined in research reports. They go on to suggest that in many cases the population may be identified based on sample characteristics and relevant eligibility criteria (Polit & Beck, 2010). This certainly was the case with this research into ageing with SCI. The target population was identified and refined by having clear inclusion and exclusion criteria which depicted a defined population.

4.5 Design of the Present Study

Outlined in Figure 4.2, the present study adopts a mixed methods sequential exploratory design, where the findings of the qualitative research phase assisted with the development of the quantitative research phase. As previously mentioned, the sequential exploratory design has been described by Cresswell (2009) as involving the first phase of qualitative data collection and analysis followed by a second stage of quantitative data collection and analysis that builds on the results of the qualitative phase.

Cresswell adds that this is often the procedure of choice when a researcher needs to develop an instrument because existing instruments are inadequate or not available. He points out that it is useful to a researcher who not only wants to explore a phenomenon but also wants to expand on the qualitative findings. Such an approach was attractive within the present research project as it enabled a research design to be developed that was pragmatic in its approach and gave the opportunity to explore the topic in a logical constructive manner.

Figure 4.2 provides a schematic overview of the overall study design.

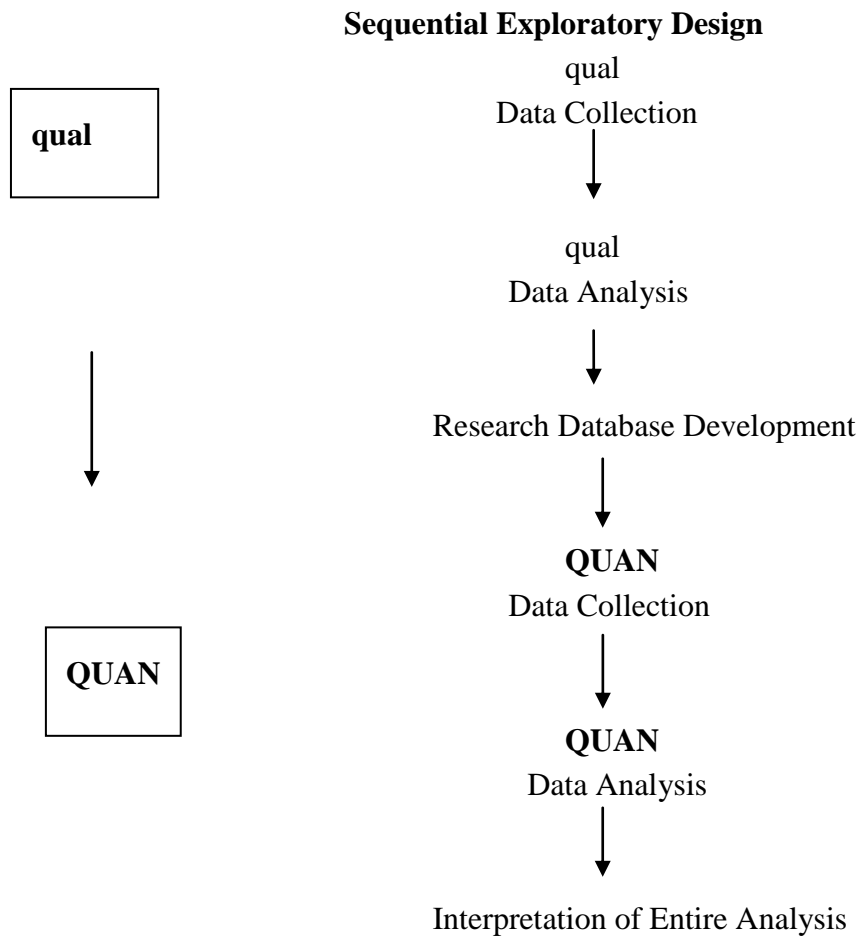


Figure 4.2 Adapted from Cresswell's Mixed Methods Sequential Exploratory Design (Cresswell, 2009 p. 209)

In Figure 4.3 the three phases are summarised showing the considerable time between each phase due to separate research designs and the need for separate Multi-regional Ethics Committee applications.

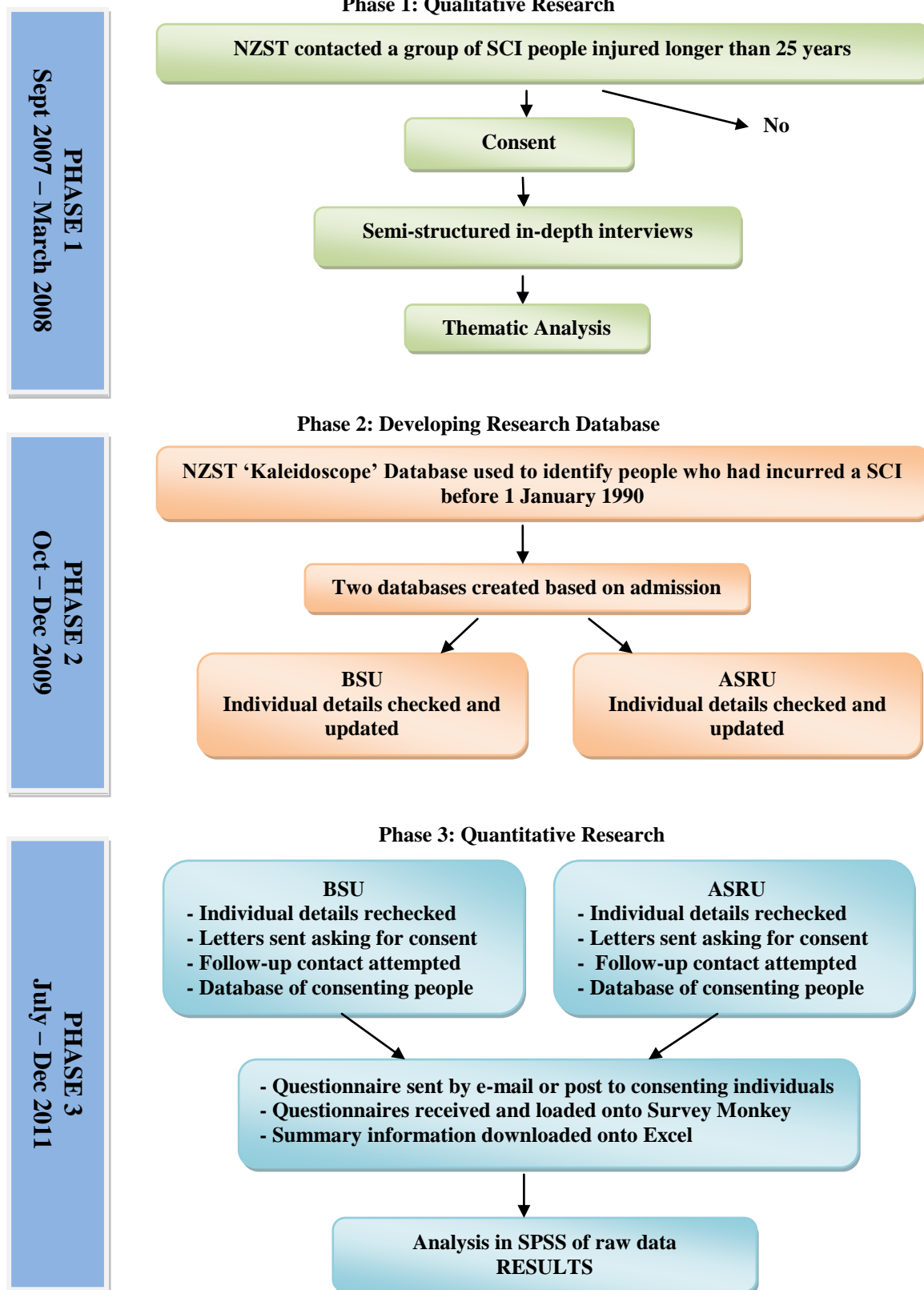


Figure 4.3 Overall mixed methods study design adopted for this doctoral research

4.6 Brief overview of methods

After extensive reading about the implications of ageing with SCI it was decided to gain better insight and understanding of the subject in the New Zealand context by undertaking an initial qualitative research project (Phase 1). This was subject to a separate Upper South A Regional Ethics Committee application (URA/07/04/026). Twelve people who had sustained SCI in New Zealand more than 25 years ago were approached to take part in a semi-structured in-depth interview. The aim of the in-depth interviews was to identify the key issues facing this group of people as they have aged with their SCI. The interviews were analysed using a general thematic approach, whereby common comments and discussions were grouped together into general themes. This is discussed in detail in Chapter 5. Such insight assisted with the development of a unique quantitative research questionnaire.

The quantitative research for this project was designed following the initial exploratory qualitative interviews to build a framework of data collection and analysis that clearly showed the issues and challenges facing an ageing group of people living with SCI in New Zealand. To be able to undertake this research, a two stage approach was necessary; firstly to establish the population of interest, in association with the two New Zealand spinal units that provide services to those people with SCI. This database development phase (Phase 2) was subject to a separate Multi-regional Ethics Committee (MEC) application (MEC/09/06/061) and is discussed as a separate research project in Chapter 6. Prior to this phase being undertaken, it was unknown how many people there were in New Zealand living with SCI. With the assistance of the two spinal units in New Zealand, two databases were established each based at the respective spinal unit, identifying a possible total population of people who had incurred SCI before 1 January 1990. The final phase (Phase 3) followed as a cross-sectional research study which is described in detail in Chapter 7. The specific aim of the quantitative research study was to determine the health, living circumstances and quality of life of these people; and to investigate their current and future service needs. This phase was also subject to another separate MEC application (MEC/11/01/002).

4.7 Conclusion

A mixed methods sequential exploratory design was developed whereby overseas research as well as findings from the qualitative research study assisted with the development of a cross-sectional quantitative research study and its questionnaire. The quantitative research served to examine the health, living circumstances and QOL of people ageing with SCI incurred before 1 January 1990.

Chapter 5: Phase 1 - Exploratory interviews with twelve people ageing with spinal cord injury

5.1 Introduction

The aim of undertaking 12 confidential individual interviews in this phase (Phase 1) was to gain insight and learn about the issues and challenges facing a group of people ageing with SCI who have been injured 25 years or longer in New Zealand. The information gained from the interviews was analysed using a thematic approach. The summarised results are discussed within the context of the national and international literature on ageing with SCI. The information provided insights into the circumstances of this group and a good understanding of the issues that they face ageing with SCI.

5.2 Methods

5.2.1 Study design of Phase 1

The design of Phase 1 was a qualitative descriptive study, based on an initial set of topics with in-depth individual interviews being undertaken and analysed using a thematic approach (Carter & Henderson, 2005; Castro et al., 2010; Cresswell, 2009).

5.2.2 Participants

A group of people living with SCI who had been injured 25 years or longer, and were resident in Christchurch New Zealand.

5.2.3 Procedure

5.2.3.1 Recruitment

Andrew Hall, the Chief Executive Officer (CEO) of the NZST, and the researcher, identified a number of potential participants who have lived with SCI for 25 years or longer, through their own personal knowledge. Potential participants were selected to ensure that there was a mix of people by age and gender; either pre-ACC (before 1 March 1974) or post-ACC; different lengths of time since injury and disability level; and with various levels of support and employment. To manage appropriate research and ethical conduct, the NZST sent a letter to the potential participants asking if they would agree to participate in this exploratory Phase 1

of the research study. Phase 1 of the study received approval from the Upper South A Ethics Committee (URA/07/04/026) (Appendix 1).

5.2.3.2 Materials

Letter from NZST

The letter from the NZST signed by Andrew Hall, indicated support for the research project and that the Trust believed the research was an important topic with information gained from the research study having the potential to benefit people with SCI. The letter indicated the researcher was a tetraplegic injured for 33 years and that the Trust was assisting the researcher by contacting people with SCI of 25 years or longer duration to ask if they would agree to take part in the proposed research study. Enclosed with the letter from the NZST were a Permission Slip, Summary Information Sheet and a Consent Form (all found in Appendix 2).

Permission Slip

The Permission Slip required the person to indicate “Yes” or “No” as to whether they agreed that the NZST could pass on their contact details to the researcher. They were then asked to sign and return the Permission Slip in an enclosed self-addressed pre-paid return envelope.

Summary Information Sheet

The Summary Information Sheet for Phase 1 explained the purpose and specific aims of the research study, what would be involved in the interview, what would happen to the information obtained from the interview and contact information should the recipient require more information or had queries. It was emphasised that total confidentiality would be maintained in an ethical manner, ensuring participants would not be able to be identified.

Consent Form

The Consent Form included a declaration indicating that the person signing had read the Summary Information Sheet, understood that they were free to withdraw at any time, and if there were any queries or concerns they could either contact the researcher or his supervisor or alternatively an independent Health and Disability advocate (contact details provided). The consenting person gave their contact details and signed the form. The researcher also signed the form. The consenting person retained a copy of the Consent Form.

Guiding Interview Questions

The Guiding Interview Questions listed the interview topics that would be covered and the general questions that would be asked during the interview. The guiding interview questions were

1. Demographic details
 - Gender- male or female?
 - Ethnic background using 2006 Census format?
 - When did you have your accident?
 - What age were you?
 - Level of injury?
 - Marital status, children? (time of accident, present)
2. Tell me about how you had your accident and the impact that it had on your life in those first few years.
3. You have had a spinal cord injury for a long time. What had been some of the issues you have had to deal with in that time? (Prompts)
 - Physically and health wise?
 - Relationships and socially?
 - Employment – history?
 - Within yourself – psychologically?
 - Relating to services such as ACC, Ministry of Health?
 - Relating to health professionals, providers, social agencies?
 - Care - community, carers, payment of carers?
4. Specifically, as you get older what have been some of the issues you have had to deal with? (Prompts)
 - Physically and health wise?
 - Relationships and socially?
 - Employment – history?

- Within yourself – psychologically?
 - Relating to services such as ACC, Ministry of Health?
 - Relating to health professionals, providers, social agencies?
 - Care - community, carers, payment of carers?
5. What do you think will be the key issues you are likely to encounter in the future?
 6. Has life with your injury turned out the way you thought it might? If it could have been different, explain how? What sort of things in the past could have helped make your life better?
 7. How have technology and changes in medical knowledge and treatment impacted on your life to date? In the future?
 8. How do you think your own experiences and knowledge have helped you? others?
 9. What impact has your cultural background had on living with your injury?

Dictaphone and transcriber

The researcher used a dictaphone to record each interview. The interviews were later played back using a transcribing machine with an experienced transcriber (who had also signed a confidentiality agreement) typing the full interview into a transcript.

5.2.3.3 Process

Figure 5.1 outlines the recruitment and process undertaken with interview participants.

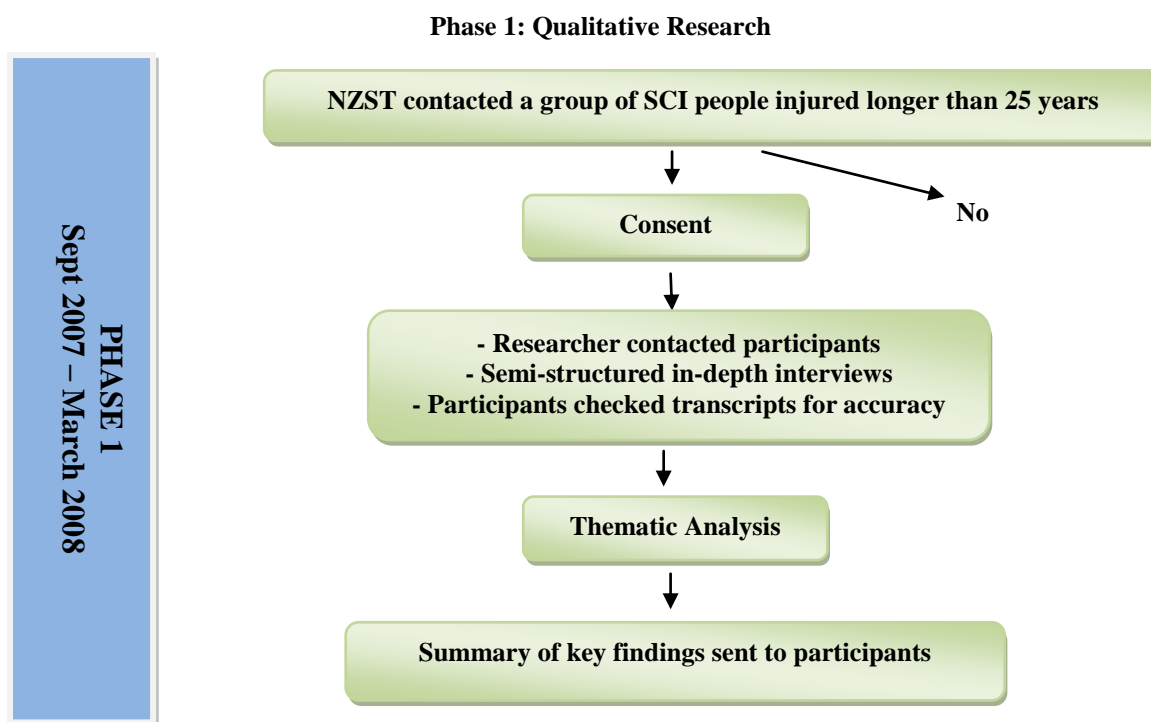


Figure 5.1 Process undertaken with interview participants

Those who agreed to be contacted by the researcher were telephoned to arrange a mutually agreed time and place for the interview. This usually was at the person's home, although two interviews were undertaken at the person's work place. Participants were given another copy of the Summary Information Sheet, identical to the one sent originally when agreeing to be interviewed, a schedule of the Guiding Interview Questions and two Consent Forms to sign. The researcher retained one signed Consent Form, with the other being retained by the participant. Interviews usually took between one to one and half hours and were recorded. The researcher, who is a registered psychologist with comprehensive interviewing skills, followed the prepared interview schedule. However, with the participants' permission, the researcher explored a topic or additional topics of interest in more detail. The subsequent transcription was returned to the participant, either by e-mail or post for them to check for accuracy and ensure they were comfortable with its content. Once the participant had checked the transcription incorporating any changes or corrections, it was returned to the researcher. The objective was to undertake 12 interviews undertaken from 5 September 2007 to 12 March

2008. All participants were told that, once the interviews had been analysed and summarised, a summary of the key findings would be sent to them.

5.2.3.4 Analysis

The researcher undertook a thematic qualitative analysis of the interview transcripts (Braun & Clarke, 2006; Carter & Henderson, 2005; Thomas, 2003). The following phases of analysis were undertaken:

1. The initial analytical phase involved reading the individual transcripts to become familiar with the information within each transcript.
2. The transcripts were then re-read with common descriptions, themes, sub-themes, and issues highlighted and noted in each individual transcript. The transcripts were then individually re-read with the relevant quote/discussion relating to a particular descriptive theme transferred (copied and pasted) under that particular theme's heading and, if appropriate, to the relevant sub-theme. This process was undertaken until all the relevant information had been extracted from the individual transcripts and collated under the identified themes.
3. The information collated under each descriptive heading was reported by summarising the key common points of the issue or sub-theme, accompanied by supporting relevant quote(s).

To maintain the anonymity of those interviewed and people mentioned in the transcripts the names of participants and the names of any individuals mentioned in the interviews (e.g. family members and spouse names) were changed. Also at times a quote has not had a pseudonym name attributed to the quote to ensure anonymity. Table 5.1 shows the other conventions used in the writing of this chapter. Rounded parentheses () were used to insert editorial notes or words not used in the interviews. Ellipses (...) were used to indicate where part of the transcript extract has been omitted for the purpose of readability and elimination of duplication; but ensuring that the integrity of the quote was maintained. Square parentheses [] were used to maintain the anonymity of doctors, health professionals or other people and to remove other identifying features.

Table 5.1 Transcription principles used in reporting of thematic analysis

<i>Transcription abbreviation</i>	<i>Use to:</i>
()	Used to insert editorial notes or words
(...)	Signifying removal of text
[]	De-identifying a person or place
<i>words in italics</i>	Indicating direct quote from the participant

5.2.3.5 Summary of key findings sent to participants

A letter (Appendix 3) thanking participants for taking part in the research study and a summary of the key findings, was sent either by e-mail or post to the 12 participants for their information. It was emphasised that the researcher was available to answer any questions they might have about the report and appropriate contact details were supplied. This part of the process was completed in October 2008.

5.3 Results

5.3.1 The participants

Of 15 people approached, 12 agreed to be interviewed, one person declined, one person failed to respond, and one person died suddenly. The 12 (10 male & 2 female) people interviewed all lived in Christchurch city. The current age range of the participants was between 45 and 81 years; their age at time of injury ranged between 16 and 44 years; and time since injury ranged between 26 and 50 years. Five people were injured pre-ACC (1 April 1974) and seven people were injured post-ACC. There were five paraplegics and seven tetraplegics. At the time of injury four people were married while at the time of the interview, six people were either married or had a partner.

Nine general descriptive themes were identified: initial impact of the injury; issues associated with long term SCI; specific issues associated with getting older; key issues likely to be encountered in the future; whether life with the injury had turned out as expected; what sort of things in the past could have helped; the impact of technology and changes in medical knowledge and treatment; how a person's own experiences and knowledge has helped them and others; and impact of a person's cultural background.

5.3.2 Theme 1: Impact of SCI in the first few years

In this section participants discussed the issues and realities of being newly injured with SCI. A primary topic was how difficult it was learning about and coming to terms with urinary and bowel incontinence. Another major issue was when participants moved from the hospital environment to re-establishing themselves in the community while living with their SCI, including finding suitable accommodation, re-establishing social networks and employment options.

Access to specialised care

All participants talked about the initial shock and early experiences incurred after being hospitalised following their injury. Regardless of age at the time of injury, their gender, or their ACC eligibility, everyone interviewed indicated that the impact of the accident and becoming paralysed with SCI was sudden, traumatic and dramatic. They talked about the difficulty of dealing with being fit and active one day to suddenly lying in bed paralysed the next day. Coming to terms with such a change of circumstances took time and required considerable thinking through to understand the circumstances in which they found themselves.

The injury was traumatic & dramatic, requiring a total rethink of everything and all my values (...). While in the Spinal Unit I took time to reflect on my life and what I wanted to do, which was invaluable. Alex

I went from a very fit person with an absolutely beautiful body, to someone who was just wasting away to nothing. I found that very hard. So that was quite dramatic that first year. Hugh

Roger had his injury as a teenager, before there was any specialised spinal care in New Zealand, and so received none of the specialised services that would come later. The first specialised Spinal Unit, consisting of four beds, opened in 1965 at Christchurch Hospital as part of a General Surgery ward. Even in later years, when there was a purpose built specialised Spinal Unit at Burwood Hospital, patients were not always immediately transferred to the Burwood Spinal Unit (BSU) – which often resulted in a negative impact on that person's health. For example, Nick, who had his injury in the North Island, did not get to the BSU until eight months after his injury, resulting in him not receiving the specialised care that would normally be expected with such an injury.

The nurses gave me the best care that they could possibly give me, but they didn't have any experience in spinal nursing, they don't have the specialised knowledge. They left an indwelling catheter in me for the full period of time which caused me to get bladder infections and eventually get stones, so I ended up having an operation up in [there] for stones. Nick

Urinary and bowel incontinence

A major initial impact was coming to terms with urinary and bowel incontinence. Those participants that were pre-ACC (1 April 1974) [Harry, Claire, Barry, Roger and Rose] perceived that the considerable challenges of urinary incontinence were due to a lack of technology and the limited availability of specialised SCI medical knowledge. As a result, many are now dealing with complications associated with medical decisions that were made during the 1950s and 1960s.

I knew that the urological knowledge at that stage was diabolical. I might have been [young] but I realised that having a U shaped tube and putting ice water into your bladder was crude, (...) the doctors admitted they didn't really know how to treat paraplegic bladder, and that was a disaster because I had leakage after several bladder neck operations. Harry

Reintegration back into the community

The majority of people experienced a number of problems as they moved from hospital to re-establishing themselves in the community including finding suitable living accommodation, re-establishing social networks, and investigating employment options. Those people who had their injury prior to ACC had no access to state funding to assist with altering their homes, purchasing wheelchairs or acquiring other necessary rehabilitative equipment. They had to pay for it themselves or receive community fundraising. It was not until 1972 that the State contributed to the purchasing of wheelchairs.

I had a couple of planks at the back door to get in. They gave me the bedpan and what not because I couldn't sit on the toilet at home. We had nothing at all. I just kicked around for a couple of years on social welfare as it was in those days. And I used to spend a lot of time shooting, going out spotlighting. Roger

Even those who were post-ACC had problems getting home alterations completed and on discharge from the spinal unit stayed at the local hospital.

I was discharged and went back to [city] but because alterations hadn't been completed or even started at my mother's new address, I had to stay in an Orthopaedic ward at [city] Public Hospital for five months. (...) We were having tremendous battles with ACC just trying to get alterations done to my mother's house to get home to commence a so-called normal life in a wheelchair. That was a very difficult period which caused a lot of stress and hardship for my mother and me.

Larry

Two people did not initially go back into the community after discharge, but moved into institutional care. Rose spent four and a half years in the Spinal Unit at Christchurch Hospital before being transferred to the [Organization] Hospital (not-for-profit private hospital that specialises in care for the seriously disabled) where she has lived ever since. Another young man felt he was not able to go home as his parents were in their 60s; he therefore chose to live initially at [Organization] Hospital and attend university. He stayed at [Organization] Hospital until completing his university degree in 1980, when he moved into the community, purchasing his own home.

People talked about finding out who their true friends were. In some cases friends that they thought would be supportive drifted away and others became closer and stayed by them.

Friends, who I thought were friends, disappeared from the scene and dwindled. However, friends that stayed by me, who knew me before my accident were to become really good and true friends. **Larry**

The experiences of getting back into the workforce were varied. Some people struggled to get back into the workforce due to a lack of confidence and it was only over time [Alex, Nick], and in some cases a considerable amount of time [Rose, Roger], before they recognised the importance of employment. Other people [Doug, John, Claire, Barry, Harry] went straight back to work or furthered their education regardless of whether they were pre-ACC or post-ACC.

Went straight back to work, working in [Organization] administration. The combination of working, the effort of being in a chair as a paraplegic, the family was neglected a bit. I did the hours at work and that just became a habit. (...) Worked for [Organization] until 2002, ended up as contract manager. I also worked at the [clinic] and in rehabilitation. Ended up with a post-graduate Diploma. **John**

Predominantly it was post-ACC SCI people [Tom, Hugh, Larry] who created a life outside the work environment, becoming involved in sport or taking up coaching sport.

I started to coach kids' teams again (...), there was a lot of negativity around me being in a wheelchair and coaching kids. Negativity was coming from two of the parents of the kids that I was coaching. At the time I was angry and frustrated. (...) So that's when I went and did the coaching course, taught me also a lot more about the skills, and the rules of it. At the time a lot of the coaches weren't teaching laws, rules, and I had a lot of the skills, they were mostly just into fitness, run round in circles round the park. It also taught me how to bring enjoyment into a team environment.

Tom

5.3.3 Theme 2: Living a long time with SCI

Participants recognised that as they grew older their health was starting to deteriorate. The majority of participants reported having long periods of good health interrupted with periodic episodes of ill-health, whereas some had experienced constant ill-health. The majority had maintained good relationships and social interaction within the community, however there was acceptance that it was different from what had existed before SCI with a common comment being “*you find out who your true friends are*”. The relationships established with health professionals, providers and social services varied in success and it was suggested that there was a need for better information. Participants reported a variety of employment situations, ranging from being retired to working full-time. In general there was a positive attitude towards life and psychological well-being. However, relationships with ACC and/or Ministry of Health varied considerably, being described as from “*terrible*” to “*good*”.

Physical health

All 12 respondents recognized that as they had grown older, their health had correspondingly deteriorated and become more problematic. This had required closer monitoring of their general health and well-being, with attention to specific issues such as skin care, bladder and bowel management, and mobility (e.g. transferring).

Things started deteriorating probably about ten years ago around 1997. Health very good, but monitor things much more closely than I did previously when I was younger and more carefree. Didn't realise perhaps certain dangers of being in a wheelchair. Comes through experience, age and talking with others in a similar situation. **Larry**

The majority of participants perceived their past health as relatively good. Some people commented that there had been long episodes of good health interrupted by periodic episodes of ill-health. Some had experienced constant ill-health on and off since SCI.

Healthwise I've been really lucky. Fortunately I've not had any urinary infections and those sorts of things. And have managed to keep out of the Spinal Unit although they tried to recall me quite a few times for reassessment, I've always refused to go. Fortunately I haven't needed them as yet. And I hope I don't for a while.

Health in those early years was not too bad but I had problems (...) then five or so years later I started having kidney stones which was my major problem and I never seem to be completely rid of them. Even though I've had stone blasting and operations they continually come back.

Participants reported current health issues, with two participants recently having a colostomy due to major changes in bowel management, and others commenting that their bowel routine had become more sluggish. Overall, six had experienced changes with urinary and bladder management; one person had developed syringomyelia which had affected his strength and mobility; and five were experiencing musculoskeletal and shoulder issues. The five paraplegics tended to have fewer health issues than the seven tetraplegics.

I think the biggest issue I had to deal with from a physical point of view was starting to work fulltime and problems associated with the bladder.

Relationships and social interaction

The majority of people reported that they were socially active but recognised that things were different from before the onset of their SCI. People talked about finding out who their true friends were and that with those who did remain friends they gained lifelong friendships. Those injured in the 1960s and early 1970s (mainly pre-ACC) talked about buildings not being accessible as there was no legal requirement for them to be so. This often restricted access and social interaction unless friends or other people were willing to assist. Also there were comments about the negative public attitudes and lack of understanding about seeing a person in a wheelchair.

The biggest issues probably early on were access, accessing buildings and restaurants and all those sorts of places because there was no building code. The very patronising attitudes that people had towards anybody with a disability. You know - it was "pat

you on the head and let me buy you a drink dear” kind of mentality and there was a lot of that around. I think it was probably my friends actually that spoke out about that to people rather than me saying anything to them.

Such experiences encouraged some individuals to become politically active with other disabled people and start up or be involved with politically active disability organizations such as the DPA and the Paraplegic Association.

[In the 1980’s] I got involved with [Organization] in Christchurch and nationally.(...) There were major changes within the New Zealand society. It was the time of the Human Rights Act and we worked closely with the AIDS Foundation and that sort of thing. I remember protesting outside Parliament for the Human Rights Act along with all the transvestites (laughing) and the National Executive which was interesting. So there was a lot of interesting things going on at that time.

Some individuals showed sustained courage and individuality, and were determined not to let SCI restrict their social lifestyle. Nick demonstrated this determination by convincing [Organization] tours to allow him to undertake a bus tour through Europe which he acknowledges now was extremely demanding and unusual. People who were with Nick on the tour slowly recognised his limitations and gave him assistance when required, to enable him to have a number of memorable experiences.

I turned around and seen this hill and I said to one American guy on the tour (...) I hate to be a pain in the arse but can you just give me a hand? Oh my God he said, I wondered how far you were going to push before asking for a hand. It was quite funny because he said ‘this guy wants a push’ so they all jumped in a line and zigzagged me up, pushing in a big line right to the top. We got to this bar at the top and one of them said, ‘oh right shove him in there’, so they shoved me into the bar. They all got a drink and stuff like that, it was probably about one o’clock, someone grabbed me lunch and then they pushed me into the centre of them all (...) you know thirty people, and they said look just tell us your story and no short cuts, we just want to know why you’re here. So I told them. They asked if I needed a hand. I said look I’ll ask you for a hand if I need one and I will possibly after this first day. I didn’t realise how much I’d bitten off. They sort of laughed and said but we don’t mind. This is our trip and we don’t mind (...) they could tell that I was quite sociable at that stage of the game.

Like other members of the community, people with SCI married, others were still married to their pre-injury partners; other marriages had broken down, and some people had been through a variety of relationships. Of the four people married before their injury, one was still with his original partner, one was separated, one divorced, and one had remarried. There were five people who were single at the time of their injury who were now married or in a permanent relationship. Three people were single at the time of their injury and had remained so.

When we got married we were told that we couldn't have children. So we had to come down to Burwood for infertility sessions and she wasn't keen on that, let alone me. I told her to go off the pill and gave it the best shot and six years later we had children.

Relating to health professionals, providers & social services

Many participants talked about how in the past there had been routine health assessments organised every year or two by the BSU but that these were no longer occurring regularly. Also some participants lacked knowledge about how to access these health services. It may be a matter of needing better information about the correct process as many of them had not received communication from the BSU for a considerable amount of time.

Received call ups for re-assessments are few and far between these days. They tend to wait for you to present with a problem before they are prepared to see you. I'm quite annoyed especially as I age and have more problems. I feel I should be monitored more closely. Larry

Yearly we would go and see [Spinal Specialist] and have a urine and blood test. At least we were kept track of. Since then, because of the ongoing number of patients, many people slip through the gap. I can't remember when I last had a full assessment.

Harry

Some people experienced traumatic experiences in hospital due to the treating health professional not having enough experience or knowledge about SCI.

In [location] I'd gone into hospital and all they would do is catheterise me and send me home. They didn't want to find the cause of the problems. They would say we can't see anything wrong with you after being catheterised and wouldn't send me to Burwood Spinal Unit. I would go oh well back to normal getting a catheter a couple of times. Nick

In one incident a participant was so frustrated that he resorted to having an operation privately instead of waiting on the public health surgical waiting list.

*I suppose you have to be a bit more assertive but it gets tiresome. Therefore with my colostomy when I saw [General Surgeon], he said you've got a paraplegic bottom I can do a colostomy in three weeks. I thought to myself it's a cost of a second hand car, put my money down and got it done. **Harry***

Employment

Of the 12 participants, two were on superannuation, one on a disability allowance, three on ACC's Earnings Related Compensation (ERC), five worked full-time and one part-time (two were receiving partial ERC to 80% of previous income).

Two participants were on New Zealand Superannuation. Both were pre-ACC. One was injured as a teenager and spent his initial years not working, living in a more rural community. He then moved to a city after working initially elsewhere, before working for 10 years for a company as a welder. The other was injured in his 40s in a work-related accident. He spent the initial years post-injury raising his family as a solo father. He then undertook part-time work.

One person, a tetraplegic, pre-ACC and now on a disability allowance, had since been injured lived in a hospital that provided care for the disabled and at the time of the interview was living in a community home for the disabled. For approximately five years after being injured this person did not work then was offered an opportunity to undertake some part-time work.

I went on the part time staff for something like four years. After that they asked me if I'd like full time employment. (...) I worked for the [Organization]. My boss actually took me out, he'd come and get me in his car and take me out there and then he persuaded me to buy a wee mini which we had altered for me to drive. I drove myself for ten years or so. Would get transferred in and out. I had this chair that this guy had developed that would swing out so that I could transfer and then they'd swing me back in again. My boss was always there and he had always someone there to help get me out of the car. I went onto the full time staff in [year]. I stayed on the full time staff until about [year] and then I went part-time again because I was having health problems. I did a lot of work from home. Then they were going through a downsizing and because I wouldn't agree to go back full-time work which I couldn't have done (...) I finished out there.

Of the three people receiving ACC's ERC, two had not worked since their injury and one had initially gone back to working part-time until his health deteriorated to the point where the employer would no longer employ him. Two of the became involved in community activities, with one coaching sport and on occasions doing motivational speaking and the other being involved in a disabled sporting organization assisting young disabled people to gain confidence through sporting activities.

I was getting recurring illness and my bosses couldn't understand why I couldn't recover as quickly as an able bodied person and why I needed extra time to recover. Sometimes I didn't even know what was wrong with me, whether it would be a bladder infection or flu or whatever, because all the symptoms were virtually the same and it was still a very new and confusing time for me, just dealing with my body and perhaps going back to work so early was not such a good thing in hindsight. Larry

Another person was on partial ERC as well as undertaking part-time work. After his injury he had returned to working full-time as a manager. He subsequently undertook tertiary education and retrained, developing his own business assisting clients in his specialised field.

Got to the point where I was not being able to work the hours any more. I just found it harder and harder to get up at that hour in the morning, get ready and go to work or whatever that day which could mean anywhere in the country. Because of getting older, you can't stay in the chair all day long, you get uncomfortable and you lose concentration. Over the last five years it just got worse and worse. I still do the odd job on contract. I've worked in a [craft] workshop so that I can do it from home and do a few hours if I want to do it (my own one being built now). ACC is supplementing my income with ERC. John

The five people still working full-time had a variety of jobs - administration, draughting, engineering, design and teaching. Three were paraplegic; one was an incomplete tetraplegic and one a complete tetraplegic. All had taken various career pathways to lead them to their current jobs. They talked about how difficult it was to get into the workforce after SCI or after obtaining educational qualifications. One, who was injured pre-ACC, was a teacher, had worked full-time and part-time, stopped work totally to raise a family, and now had returned to work full-time.

I started teaching at [school] because they thought it was probably the most accessible school there was. They had to put a ramp in for me and they said I didn't

have to start teaching until it was in. Fortunately it went in very quickly, and then when I went to [school] the office block hadn't been remodelled according to the Building Code, there was a six inch step into it. The Education Board refused to pay for the alteration or have the ramp put in as they said they only had a policy of making sure it was accessible to children, not for teachers (...). So the school actually paid to have that ramp put in and also little ramps in various places to give me access to other places. It was very much attitudes and bureaucracy.

Harry, who was pre-ACC, had worked in a specialised manual occupation before his SCI, and had struggled to return to the workforce. Initially he made carvings and children's toys in his garage at home. He found it socially isolating. Eventually he obtained work in a manufacturing firm in a job for which he had originally been rejected. He found he started to meet people and socialise.

Two months later he rang me up and, I can always remember that because my first job as a fully paid paraplegic was sorting out broken drills. I thought how far can you come, from the [Organization] in charge of hundreds of men and millions of dollars and now I'm sorting out broken drills. Then I thought, this man's paying me, I will do the best, soon I was sharpening the drills, it wasn't long before I was ordering them and after ten years I was a factory foreman there. (...) I wanted a (new) challenge. When I left [Organization] I took up a position as administrator officer at the new [Organization] in 1980. (...) I was rather horrified to apply for the job and get it and found that when I came in I had to create my own job.

Doug was a complete C4/C5 tetraplegic was post-ACC. He felt that he was not disadvantaged working towards his postgraduate degree as most of it was using his brain and his computer. Although in hindsight he does recognise that it was difficult.

Probably looking back I would say getting the degrees was very hard and I wouldn't want to do that today. Like we're talking about the 70s, right? So nobody had personal computers. I had a golf ball typewriter and to take notes and do a degree with, you know, not being able to write terribly fast on the typewriter, there's no way as it was extremely physically demanding. (...) Like the first year I did too much and I ran into trouble about Easter in the first year, you know with my health. So the first year took two years and, but the rest of the degree, you had to do, the final academic year, you know in one year. So you know it's bloody hard.

Psychological well-being

Not everybody commented on how they felt psychologically. Those who did generally felt they had coped well over the years and considered themselves to be “survivors” often having overcome major health and physical obstacles to achieve the things they had done. The clear majority had a very positive attitude towards life.

I’ve always thought positive because I’ve had good health- lucky, you know and I’ve had good people around me. Lovely wife and now with my children, there’s so much to do and I keep myself so busy that you just keep going. Feel I have a great quality of life. Probably a lot of other people say they don’t. But I feel like, look if I was able bodied there’d be shit loads more I’d be doing. But where I am today I am in good space - we go on holidays, we go camping. The kids go to school. I spend a lot of time with my children going to all their sports and events and stuff. I’ve got a good job that I like, you know, it’s what I want to do. So yeah, I feel I’m quite lucky actually. Nick

Participants acknowledged that there had been difficult times as well. One was injured in the 1970’s as a young man talked openly about the difficulties of coping with general life after his marriage breakup. Another talked about having “down days” but had learned there was always someone less fortunate and that kept him going. Two participants talked specifically about how complications from health issues had affected their general wellbeing.

It has taken a while to come to a realisation, you get to an age where you’re supposed to be able to sit back and relax and enjoy a few things – only to find that health problems interfere with this. John

One participant made reference to how the medication valium taken for spasm had made him feel depressed. The specialist switched his medication to baclofen in 1976 which made a big difference to his psychological well-being. He adds that improvements in technology, medicines and medical equipment (wheelchairs, computers etc) had made a huge difference to his QOL and well-being.

You couldn’t actually get urinary aids for a while. So you had to actually get a condom and cut off the end and use it like a spigot thing. And the adhesives, there was nothing like there is now, like they only came along after a year or two, and skin trouble, and they fixed all that up with new technology so you know, um, that, I think time-wise if I’d had my accident ten years earlier it would have been just too bloody

hard. It was hard enough at the time. If I'd had it a bit later things would have been a hell of a lot easier. Doug

Relating to ACC, and Ministry of Health

ACC was established 1 April 1974. Of the seven people (mean time injured: 29.4 years) under ACC, their opinions were mixed. Some considered their relationship with ACC was “terrible”, with others commenting that it varied at different times over the years when there were changes in policies and/or personnel. A lack of information about entitlements was identified as an issue. Others found that overall the relationship with ACC was positive. Three people commented on the allocation of carer hours, what they were allowed to do and/or the low hourly rate carers received.

ACC pays for about five hours a week for someone to do my housekeeping. It doesn't allow them to do anything to do with the gardens or lawns or outside which always is annoying. They even say that cleaning windows is not housekeeping. I fail to see how the housekeeper is not allowed to clean windows. Doug

I could actually probably get a lot more than what I'm getting off ACC at the moment. But I've always held off for equipment I would really need, my theory was I always will go to ACC when I need them. What really hurts me is the fact that when I do go to ACC because I need them, it always turns into a battle. (...) I needed to do more training so I paid for my computer courses but I asked ACC to help out with some cost towards my computer equipment. It took me two years of arguing with ACC for what I thought I was entitled to. I paid for my course which they should have actually paid for. (...) At the end of the fight they got a specialist in computer equipment and he was an independent person and he turned round to ACC and said 'why we are arguing?' That was two years of arguing with ACC. Nick

When I was working full time - good, since I've stopped working a little bit more complicated. Overall mostly pretty good but..... they're (ACC) always trying to push you in. Fair enough I suppose in some ways. They sort of don't quite get the concept that it's not going to happen full time. When you ask for things, depending what it is, it's more bureaucratic going through the process of getting things. They don't make it easy. So I've had to take them to review, and even to court, which has been annoying and expensive. John

The five people (mean time injured: 42.4 years) injured before ACC was established had their care paid for by the Ministry of Health and social support by the then Department of Social Welfare (DSW). Each person had their own personal story about how they survived with little government funding and support. For example, one was a founding member of a disability organization which assisted others in wheelchairs by providing peer support and hiring equipment. It was only in 1972 that the government began to give financial assistance with the purchasing of wheelchairs.

This wheelchair I'm sitting in was the first one I got free. Every other chair before that, over forty years, I had to pay for. The first wheelchair I ever had I had to pay for with money I got from the compensation money but after that because I was working the next two chairs I had to pay half. It was five thousand dollars for the first one, so I had to pay two thousand five hundred. **Rose**

I think I was unaware, probably in the early days, that you could get any sort of assistance. Small alterations to your home, we paid for all our own ramps and bathroom and all that sort of thing and kitchen and so forth. I had a high kitchen bench for thirteen years until I did go and get a grant and got the kitchen remodelled.

Claire

(...) it was pre-ACC, so we had a strong welfare committee that had ramps, toilet chairs, spare chairs, who could assist, who could help you with building a hand control. Even after 1972 when free wheelchairs were supplied, there was still a need to help each other with peer support. Quite a long time really, 1965 to 1972; you had to buy your own. We had to smuggle money overseas to get a wheelchair back. Modifications started I think a wee bit later on. (...) It was just life. You got on with it.

Harry

One person injured in the 1970s and who is now in his eighties, feels he is getting better support services now with his care being coordinated by the Canterbury District Health Board's (CDHB) Older Persons Health Care Services rather than when his care was being coordinated under the Ministry of Health.

5.3.4 Theme 3: Specific issues associated with getting older

A variety of issues associated with getting older were identified by participants. These included a wide range of increasingly frequent physical health problems: musculoskeletal deterioration causing pain and decreased movement, strength and mobility; increased problems with the immune system; urinary and bowel problems; respiratory complications all resulting in deteriorating health. Maintaining relationships and social interaction was more of an effort, especially to get out and about to maintain relationships. However participants recognised the importance of maintaining close relationships, especially with family. It was more difficult to sustain full-time employment, mainly due to fatigue, and many wanted to reduce the number of hours devoted to working. Some participants recognised the importance of maintaining a positive attitude by getting the most out of life. Others had identified that it was an effort negotiating with ACC and/or the Ministry of Health to get recognition that changes in individual needs required increased funding for care and contributions to housing changes to maintain a QOL. There was a strong feeling among participants that health professionals had not recognised that they were getting older and were developing secondary health complications and needed to have better access to SCI specialist advice and reassessment. Some people recognised that they were less able to rely on their partners and they needed to have more care in the home, which had been difficult to accept, especially as this inevitably meant less privacy.

Physical health

All participants recognised they were starting to encounter a wide range of physical issues and complications associated with getting older. The specific issues highlighted were problems with shoulders and neck, increased pain, decreased movement and strength, deterioration in bladder function with an increasing number of bladder infections, kidney stone problems, bowel problems in some instances needing a colostomy, brittle bones and arthritis, decreased respiratory function resulting in more chest infections, complications from the original injury, decreased mobility resulting in transfers being more difficult, and the need to switch from a manual to an electric wheelchair. The impact of their deteriorating health was considerable.

(...) when you're young you feel bullet proof to an extent that you're still able to physically do things, climbing in and out of cars is not a problem, even doing it several times a day. The normal getting in and out of the shower, on and off beds, on and off chairs, lounge suites, all of those things are no issue, but all of a sudden as

*you get older that is actually really, really hard work. And even pushing a manual chair round, coming up the ramp is no longer as easy as it used to be and it actually has a long term effect and if you do something, particularly physical early on in the day then you pay for it all day long. Then of course at night time when you got to bed you've got to lie on your shoulders, so you have a very poor sleep. I've just found all of a sudden that it is actually having quite a major impact on my mobility, capability to get around. Everything is more of an effort now and you live with pain a lot. **John***

*(...) early on you know, you have your accident and you get over it and you get a bit stronger and then you sort of feel like, good you know, I'm right now. I wouldn't want to be one of those poor buggers with MS who never knows where they are. So you carry on, you think things are pretty good and then after about twenty years you start to get a few problems and then as I'm up to thirty three years now, the problems seem to be coming a bit thicker and faster so I think in fact that I aren't quite that stable. Basically I'm ageing faster than you would if you weren't in the chair. So problems are coming along now. I have to deal with having to go to see medical people whereas for the most part for twenty years, I didn't see anyone. **Doug***

There was recognition that the medical profession and spinal specialists were learning how to treat their health issues as they occurred and that they were “*pathfinders*” for people with SCI who would come after them. One person said he felt like a “*guinea-pig*” at times. Almost all participants had a very positive attitude to life, determined to make the most of it despite the obstacles.

*Been hell at times and we've come through it haven't we? No, not all of us. That's the main thing isn't it? We're still going, God knows for how long. I'll live as long as I can and die when I have to. Ok, for a long while I did transfers with a sliding board and that got just too much. Now they got a hoist. I just lost the strength. I'm not allowed to push myself too much with my stomach you know. And now I've got a hernia on my stomach wall. I can't do anything about it but [Spinal Specialist] says it'll go for years. It makes it a bit hard breathing now and then but it's all right. **Barry***

One person had stopped driving, due to pain and loss of strength in his shoulders and arms, and had started using an electric wheelchair. Often the physical deterioration was slow, with people taking time to recognise that it was becoming a major health issue affecting their QOL. The transition from a manual wheelchair to an electric wheelchair was often a difficult

psychological barrier for people to overcome as they had to accept that they were becoming more disabled. Two people talked about deciding to personally take more control of their health especially in the use of medication, often against medical advice.

I take a couple of muscle relaxants, one for my bladder, one for general spasms and I've popped antibiotics for the last ten years, every day, as a maintenance thing for my bladder. And that's given me a quality of life that I didn't have before. And I don't intend to stop even though the side effects will damage my lungs because of the antibiotics I'm taking. (...) I've got a bit of a bullet proof attitude going on so, my own ego I suppose. [Spinal Specialist] seemed frustrated with me this time, the specialists have been frustrated with me many times over the years and that's probably where, we didn't really knock heads as such but I'm going my way and he just decided that that's fine. Alex

Relationships and social interaction

Participants who commented on relationships and social interaction discussed circumstances that were unique to them. John, aged in his fifties, commented that he had a good circle of friends but recognised that as he got older it was more difficult to get up and down steps in his manual wheelchair therefore making it more difficult to go to places without assistance. Barry, aged in his 80s, talked about the importance of his close relationship with his children and grandchildren, whom he saw regularly. He commented that it was important to have a positive attitude and that he was “very happy with life”. Tom, aged in his fifties, who had his wife undertake his personal cares, was encountering a new situation. His wife was also ageing and experiencing physical issues that would affect her ability to continue to undertake his personal cares.

I'm getting in a situation now where, my wife's knees are getting wrecked. And she's had them checked out and that has started from me, just stress of lifting me and everything, doing everything for me and things like that. But then after a period of time we've figured out that it's just gone through wear and tear and now it's all crunched up and she needs a whole new knee, knee joint in there. And she's going in for that in six months time. I'll have to go check out community care, some other carers. All my family and friends have put their hand up and offered to help. I think that's really good that they do that. But I still need the proper carers for my toiletry, after the changing of my supra pubic and things like that. Tom

The person, who had lived in a hospital environment since being injured, had recently moved into a community house living with four other disabled individuals and had found it a difficult adjustment to make because living with people in a flatting type situation was all very new.

I used to go out and play bridge once a week with a bridge group. Used to go the library once a fortnight but I actually haven't belonged to a library since I've been here [community home] because I don't do as much reading. I used to read prolifically like perhaps a couple of books a week whereas now I go through probably two or three a year. Spend much time on the computer. I do a lot of research on line and stuff.(...) Ten years ago I would have been living in a hospital with other tetraplegics and paras and so you can manage things. Whereas, now I'm living with people who are really different. Sometimes it is very frustrating. The person in the next room, he's one of those people that gets in and out of bed at night time and even though you can talk to him you can't really, I don't think he's really understanding what he's doing to me. I don't think he understands that his getting out of bed wakes me up. (...) In a flatting situation you could probably do something about it and if you didn't like it you could move out. Whereas, I can't. Can't even shift rooms around. In the hospital well I could always get a room change. But down here you're stuck.

Roger, now in his sixties, felt he was forced to retire due to ill-health. He had originally thought he would not still be alive therefore had not attempted to save additional funds for his old age, and this now resulted in him relying solely on his New Zealand Superannuation. This had meant tight budgeting with him having to forego some of the things he used to do when he was working, such as his regular fishing and four wheel driving expeditions.

With the sports we used to kick round a lot and there was a lot of other different people used to sit round after that. And then always with the (....) club was always a group of us there. And I used to do a lot of salmon fishing, I used to do that on me own but you (get) to meet a lot of people round the river. Which helped me a lot. (...) Got rid of the [vehicle] about three or four years ago. It was getting a bit sick so I never had any money to fix it up so I got rid of it before it packed up. One of the worst things I done, getting rid of that. Used to get up in the back country all the time.

Employment

Three people commented on how ageing with their SCI was affecting their employment. They were finding it more difficult to sustain full-time employment and wanted to reduce the

number of hours devoted to work. One person aged in their fifties was hoping to reduce to part-time work in the next couple of years. Two people mentioned physical issues such as back and neck pain. Alex wanted to move to part-time work and commented that it was hard to stay positive and that the mental stress of working full time caused physical stress on the body. He noticed that when he was on holiday his whole body felt more relaxed and he did not have the physical discomfort he experienced when he was working. Also he commented that it had been impossible to get employment insurance due to his SCI. Doug was in the process of reducing the number of days he worked.

I've found just even in the last six months my neck, doesn't cope after four full days, so I'm thinking of knocking another day off. So three days. If I do that I'll have to investigate earnings related compensation. I don't know what I can do about that other day that I take off.

Psychological well-being

Two people commented on their psychological well-being as they aged with SCI. Roger aged in his sixties talked about how important it was to stay positive and get the good things in life no matter how small. John aged in his fifties, talked about learning patience to cope.

I think also over the years I've learned patience. I don't get upset when things go wrong. Sometimes I used to be pretty impatient and if things or people didn't agree or did things that I knew was wrong, I would let them know. Nowadays I say well whatever, I may not agree with what they do but I'm not going to get upset about it. So you know that's the one thing about being in a chair it does teach you patience. Because you have to have patience at times when you want something that's on top of the shelf and you've just got to wait for someone to come and get it. And you learn not to get angry, the fact that you want it and you want it now. Someone will say 'I'll be there in a minute' and ten minutes later you're still sitting there.

Relationships with ACC and the Ministry of Health

Two ACC clients found that as they grew older and their needs had changed, it had been difficult to negotiate with ACC on funding for increased hours of care. In Hugh's case, he sought a definitive contribution to the building of a new home to meet his changing needs and maintain his QOL:

The old house did not meet my needs. The process has been less than efficient. (...) only productive thing was we actually got a letter back on mediation stating what they

would fund and what they wouldn't fund. So that we can take that to appeal. The initial letter it just said request denied sort of thing. After having gone through the whole process of being assessed by OT, going back to the house we used to live in, that the house was not suitable. And any alterations to the house would be impossible so as a result of that Karen and I looked at buying a house. There's not one house on the market today that you can actually buy if you use a wheelchair.

Two people talked about the lack of funding under the Ministry of Health as they aged with SCI. One had opted for hospital care rather than live with her mother and receive minimal care. The other discusses the lack of fairness of funding between ACC and Ministry of Health.

*There is a lot of inequality (...). You know to get a wheelchair, to get your car altered, you know it costs - I got about eight hundred and ninety dollars towards changing my car over to hand controls and it cost two thousand dollars. And you've got to be working to even get the eight hundred and ninety. You pay your taxes like everyone else and you don't get anything out of anything really do you? It's an absolute fight to get a replacement wheelchair. They just want to give the old one new tyres or upholstery and say it's as good as new. It's as though we don't deserve the latest technology that ACC people are entitled too. And you have to prove that you are working and need a new chair. I had a real fight to make them let me keep one old chair so that I had a spare. They said I didn't need a spare as they could fix my chair within a couple of days. What was I meant to do in the meantime? Stay in bed? **Claire***

Claire also pointed out that she incurred her SCI prior to ACC and had never received funding for home help because she was working. However, when her husband had a hip replacement under ACC he qualified for home help.

Relationships with health professionals, providers, and social agencies as people aged

There was consensus among participants that spinal specialists were learning as people aged with SCI. There was a strong feeling that the BSU had not kept in touch with the ageing group of SCI people, many of whom had not had a reassessment for many years. One person recognised the importance of having a good relationship with his General Practitioner and the need for regular checkups by the spinal specialist.

Relationship with the spinal unit over the years I think has deteriorated, since they stopped doing re-assessments on a regular basis. That's where I think the whole system has fallen down. My last formal reassessment was in 1998. We stayed in

overnight. And it's like if you've got a problem in your car you get it fixed. Anything that goes wrong it gets fixed and I know over the years that although a lot of people didn't like going back to the spinal unit, the old story, everyone's gripe, they'll find something wrong and keep me in. My philosophy was if they found something wrong and they can fix it.(...) And now not being regularly assessed and we know there's been a couple of people who have died just suddenly and you wonder perhaps if they had their annual checkups would they still be alive or not? Hugh

Community care

Three participants talked about the need to relieve their wives or partners from undertaking their cares. One person, an incomplete tetraplegic, has had his wife undertake his cares since his SCI in 1980s and is now faced with having to find carers as she requires a knee operation as well as having sustained back deterioration. Another person, also an incomplete tetraplegic, also injured in 1980s, was physically independent but as he has aged he is no longer able to transfer independently or undertake his cares. Having a sliding board has made a big difference transferring into and out of the car with his wife's assistance. Having carers coming into the home on a daily basis is a concern for him and his wife because of the lack of privacy, but he recognised they were going to have to adjust. A third person, injured in the 1950s, felt frustrated because now he could no longer easily transfer in and out of the wheelchair and could no longer do the house maintenance as he used to. He needed assistance to maintain the house, which he could not afford.

Doug, a complete tetraplegic who is single talked about the importance of having stability with the same carers coming regularly.

I've had the same people for eleven years in one case and eight years in another. So, in fact I was reading something in a magazine the other day, in the Spinal Network News, about looking after your carer and making sure that they had holidays and all this sort of thing. And I thought, you know, (name) never had a break in ten years. Comes every Monday to Friday and the only time she's had a holiday is when she's gone with me on holiday. And (name) the same. She comes every weekend; she's been doing that for eight years. Yeah, great, you know probably thick skinned to put up with me for eleven years.

5.3.5 Theme 4: Living with SCI

Considering whether life had turned out as expected, what stood out was how people had accepted their lives as they were and had an attitude of just “*getting on with it*”. Some participants did not think very far ahead and took life as it came, whereas others initially did not think ahead but had changed their attitude as they grew older and had more responsibilities, such as families. Some participants were pleasantly surprised that life had turned out better than they initially thought it would, whereas one person indicated that retirement had turned out worse than they expected.

Others never thought very far ahead and took life very much as it came.

It's not something I've ever actually thought about. Never ever really given much thought as to what it should be like. I mean to say you only get one shot at it so hey you've got to enjoy it as much as you can and there's always, shit happens anywhere but on balance, no there's more good things than bad things. I feel like I've probably had better than I could have expected, given the physical condition, yeah. John

Others did not think ahead initially, but, over time, have changed their thinking not only because of being in a wheelchair with SCI but also because they had grown older and had more responsibilities, such as families.

In the initial first years when I was single I never tended to want to look too far ahead. You know, I was always living for today. (...) I am thinking a lot more now because I have others to consider and I've got children. It's ageing. Well ageing and having to get round. Also thinking about other people. You know before if I couldn't get from A to B and I was sitting in the middle of the road, you know, for a couple of hours, I don't care. But sitting in the middle of the road with the wife that wants to get somewhere, and shopping, or the kids want something to do, you get an earful. Nick

Doug believed that his life had turned out mostly as it would have if he had not had SCI but then adds he is also amazed at what he has achieved despite his disability. Others suggested that their lives had turned out better than they had expected.

I think in many ways life's turned out better than I thought it would when I was a teenager, before I had my accident. I mean I really didn't know how life would turn out then. But I think it's actually given me the opportunities that I would never have had before. I don't know whether I would have done much travel. I probably would have done a bit of teaching, got married, had kids and just plodded on. But you know

I've done all this travel, I've met lots of interesting people. I think in many ways it's a much more interesting life than I would have had. **Claire**

Some were surprised how life had turned out for them. They had achieved more than what they expected and were positive about life generally.

Yes, I guess I am following the path that I thought that life would be when I was first placed in a wheelchair. I'm quite surprised at my longevity really though. I was told that in the early days that life expectancy perhaps would be no longer than fifteen years. I'd sort of like to prove them wrong in a lot of cases. Very much a big mystery and since being in a wheelchair it's been a huge learning curve but I've come to the point of realization now of how to look after myself as best as I can and hopefully continue. In terms of being tetraplegic I'd rate myself as being quite fortunate. I don't have any difficulty comprehending it; I just accept it for what it is now. **Larry**

One person who had lived with SCI for over 50 years indicated that his retirement had not worked out the way he thought it would, in terms of deteriorating health and reduced income.

No it hasn't. Oh just the way the pressure area and what not and health packing up a bit. I'm not doing what I thought I would have been doing, or as well as what I would have been doing, which is frustrating. Plus only being on superannuation you're just about broke all the time. With the price of petrol I can't go gadding off to the river fishing every other day or something like I used to. I'd think nothing of going down to Rakaia today and then I'd be home tonight and then I'd go down there again tomorrow. **Roger**

5.3.6 Theme 5: Key issues likely to be encountered in the future

Some people suggested that the issues they would face in the future would be similar to any person ageing, just that they might occur a bit earlier due to their SCI. Issues mentioned included the point at which to reduce the number of hours working, and the need to get assistance in the home or downsize their home. Those participants who commented on physical deterioration as they became older tended to be people who had or were experiencing difficult periods of ill-health. They recognised that they were going to have to deal with their body wearing out, and would need to cope physically and psychologically with becoming older. This involved accepting that they would become more dependent and require more assistance, care, equipment and technology to maintain an appropriate QOL. Two people

commented that medical and technological advances were likely to help SCI people in the future.

*I don't know whether they can keep removing the (kidney) stones or not. That'll be the major thing. The next thing is dialysis. I don't know how I'd deal with that. Because I know able-bodied people who have not been able to cope with it. **Rose***

*I think about wearing out. I think the thing that you probably think about a lot these days really (...), not that I dwell on it in any morbid sort of a sense, although it sounds morbid to mention it, because you've really got to wonder what your longevity is. Particularly, lately with a lot of our cohorts popping off. So that's sort of, you know, raced up a bit quicker than I thought. **Doug***

*Oh, needing a lot more. Adjust to that and also you've got to realise it's going to happen. Because the last thing I want to do is go to permanent care. I want to live in my own house as long as I possibly can. That's pretty important to me. Actually I'm quite looking forward to the future. When I get the mobility van ACC can get me, there are lots of places that [wife] and I haven't been to that we'll be able to go, just get out and go. On a waiting list for that. **Hugh***

5.3.7 Theme 6: Things that could have helped in the past

Participants recognised that in recent years there had been considerable improvements in medical knowledge and technology (lightweight and electric wheelchairs, accessible wheelchair vehicles) which had improved people's life expectancy and long term QOL. Issues identified in the past that could have helped included better communication with ACC and a relationship with individual case managers which would have benefitted everybody. Alex, injured as a young man, wished ACC had assisted more in establishing his work environment, such as providing computer equipment and software to assist him with his work. For those pre-ACC participants injured before the 1st April 1974 there was a strong desire that they should receive equality with those who later received ACC funding. One person wished he had opted for a colostomy much earlier as it would have made a big difference to his QOL. Another discussed how a recently improved living environment and the use of electric wheelchair had greatly improved his QOL. A further man regretted having his wife undertake his personal cares as her health was now deteriorating. He now recognises that he should have had outside carers come into the home to assist him earlier.

Oh, I would definitely say technology would make life easier. As far as having better outcome I think improvement in medical science too would probably have meant a better outcome in terms of the things they can do for you immediately post accident. Whereas, there is far more intervention now. Thirty three years ago they'd make you comfortable and you know, didn't really expect you to live more than a day or two. Then when you did it sort of well take him to the wards, he is still alive. Back then there was absolutely nothing done, no tractions, no surgery, absolutely nothing. Neck just left to heal the way it was. Now I think you know, if you had the same accident today I think you'd probably have a lot more done. You'd have a better range of motion. You'd come out of there with better skills in terms of just bladder and bowel management. All that sort of thing you'd be off to a roaring start. And study, that's a thing, it would be a hell of a lot easier with the internet and computers. I think yeah, people have got it, and rightly so, a lot better things. Doug

I'm in a comfortable position in a nice home, in a nice environment and just happiness being in this environment has definitely enhanced the way I look at my life, at present. Initially I was reluctant to go into an electric, power chair, um, wanting to remain active, more active in my manual chair; I feared losing strength from not propelling myself around with my arms. However, that really hasn't occurred and the power chair certainly does offer a hell of a lot more independence than a manual. Because I was able to drive before, being placed in the electric power chair I was still able to get a suitable vehicle, a self drive vehicle to carry on with my, yeah to carry on driving. Also I think knowledge in urinary care has a lot to do with my longevity, considering a lot of tetraplegics tend to die or have a lot of complications with their urinary tract, whether it is kidneys or bladder problems. So urology does play a huge part. Larry

5.3.8 Theme 7: The impact of technology and changes in medical knowledge and treatment

Many participants commented on how improvements in technology, medical knowledge, and treatment as well as the development of new medications had made a major difference to their QOL. Technological advances included lightweight manual and electric wheelchairs which had made it much easier to be more mobile and independent. Legislation and building codes had greatly improved wheelchair access to buildings that had benefited all disabled people.

*I was sitting on an old foam cushion, got a [pressure] area, having a new modern cushion made a tremendous difference to my life. Almost turned it around I think. If I'd continued using that old foam technology it would have been a bit disastrous. So the wheelchair and the cushion. And I suppose the advent of the wheelchair hoist to put the wheelchair on the roof of the car. I'm saving my shoulders. **Harry***

*This electric chair, yeah. Especially this chair has been great. I can go from here to the square and back. And I've got a hoist above my bed. **Barry***

*I can now go for a walk with my wife. I can go shopping, put things on my lap (...) it saves my shoulders, it's good for my health, just makes me more independent, I can do more things. Go out and do things more. **Hugh***

The development of computer technology and software had greatly assisted many of the participants, especially in the work environment. Software, such as the dictation voice activated system Dragon Naturally Speaking, and drawing software had made life much easier for people who do not have proficient hand and/or keyboard skills.

*(...) technology has changed my life quite considerably, especially with the computer and my work environment. Without having had that education back in my earlier days I always struggled, I felt that I wasn't intelligent enough, I knew that I could do the job but I didn't have the qualifications to get the job which hits your confidence.(...) So the technology coming forth and me being able to learn that and take it on board is something I ran with. Had to change, and that gave me confidence and that's brought me forward in a lot of areas. **Nick***

Participants commented on how wheelchair access in the community had greatly improved over the years, with changes to the building code. People had some confidence that they could move about with relative ease with good wheelchair access.

*Attitudes have changed towards things I think as far as when I was first in a chair, you know the open European style shower with tiles from the waist up. Hand held showers were only just around then and they were very primitive and crude and didn't work that well. (...) The building code has done a lot, especially as far as getting out and being social. Pretty confident these days that there's going to be a disabled toilet where you are. It's absolutely fantastic considering the problems I had a few years back. **Alex***

*I like going to the movies, not so much, well to see the movie, I still get a buzz out of buying my own ticket. Going to the toilet if I want to. Going into the movie theatre and leaving when I want to. Because I came through where my wife had to take me up the step in the fire escape and everybody would stare and of course the eyes are getting adjusted and you'd sit in the aisle and then the usherette would say 'will you move sir?'. So going out was a real mission. Whereas now, you're a member of the working men's club. People treat you well, and I suppose if the attitude's good out, it comes back. Very rarely now do you get something in society where you think, ooh, gee that's a bit off. **Harry***

Two men commented on how new medications had improved their QOL; one acknowledged recent advances in medical knowledge had helped him win his battle with cancer. Three participants had chosen to have colostomies which they considered had greatly improved their QOL. The procedure had eliminated problems associated with bowel leakages. Four participants in recent years had been required to have urological surgical intervention with supra-pubic catheters being inserted to remedy problems of urinary tract infections and reflux. Nick talked about the need to have better communication between the general hospitals and spinal specialist to ensure that SCI patients received the specialised care required.

(...) better communication probably between the health sector and what's available. If there wasn't this, mentality between hospitals it would better (...) and it took two days to get a phone call down to [Spinal Unit]. I mean they endangered my health. [Name] Hospital thought they knew better, one thing I do know about, I probably know more about my body than most doctors.

5.3.9 Theme 8: How a person's own experiences and knowledge had helped themselves and others

It was acknowledged by many of the participants that they had learned a considerable amount from "the oldies", people who had SCI before them, whom they had met while playing sport or had met in the Spinal Injuries Unit. Participants suggested that they had learned a considerable amount personally over time and in some cases it had taken years for them to understand their own bodies and how they functioned differently due to SCI.

I think because I've always been given a lot of knowledge from the oldies, I mean I'm one of the oldies now but in the past when I was coming through, it's always been inspiring and it's given me the basics to live. But it's always been someone coming

through that's given me that extra bit of information that's helped me along on the way and I think that, you know, that's why I'm never scared to ask any questions. Nick

I think I have more of an understanding now of my disability and how things work. Before, you'd have all these problems, right you'd have sweating or something or something's not working you know, and you didn't really know what's going on. You're just putting out fires for a long time. And then after a while you notice patterns (...) And it all seems very easy to manage then. But that just takes years really and you can tell people that but there's probably no substitute for just going through it and learning it. Doug

Because those interviewed had lived with their SCI over long periods, many had helped others understand and learn how to adapt to their disability. Some considered themselves role models for disabled people generally. One man talked about being involved in setting up [Organization] started locally and nationally as there was a realisation that getting people involved in sport would assist with integrating people back into society.

Being, I guess, a role model for some other people and even kids at school see that even if they've got a disability they can still do the sorts of things that other people do. You know, we have had kids at school in wheelchairs and things and they've been good achievers. And you hope that you're some sort of model for that kind of thing. And also you know if any of those kids happen to be unlucky enough to be in an accident and finish up paraplegic or tetraplegic or something that they'll think, oh well you know we can do these things. You don't know what sort of influence you have on people. But people certainly remember you, the kids I've taught certainly remember me. (...) There was a woman came out and she was hanging the curtains in our new block at school, she said, oh I remember you, you taught me at [named school]. She told me who she was and oh my goodness. Claire

Certainly being one of the early paras you realise that there was tetraplegics facing a grimmer time than you were. Even paraplegics were having a grim time. So that's where the formation of the [Organization] foundation, and [Organization] association started, to do sport, to feel part of society. Because we realised in those early years, New Zealand is a sporting nation. It loves sporting heroes. If we can get in there, they're going to look at disability in a different light.(...) we thought if we can get out there and achieve sporting wise, society's going to view us a little bit differently. And

one of those examples, they organised the basketball game behind the old hostel, one basketball hoop in the middle of the basketball court, we had old chairs, it was hopeless. I said to [Spinal Specialist] this is absolute bullshit. He said see those two over there, and the two people watching, they're going to make a decision whether you get free wheelchairs. So we continued. I felt that you were a guinea pig putting up with a lot of stuff to better the situation. Harry

5.3.10 Theme 9: Impact of a person's cultural background

Five of the 12 participants specifically said that their cultural background had no impact on them living with SCI. One man said he was New Zealand born but from a minority ethnic background did not feel that it had any significant bearing at all and he considered himself very much a Kiwi. Another identified as having Māori ethnicity also indicated that his cultural background had not affected his life with SCI at all. It was only recently that he was starting to learn about his cultural heritage.

Six participants interpreted the question to relate to the support received from their family members and friends and how their support was important in helping them come to terms with living with SCI.

I would say family, my upbringing before the accident, family support after it, all those things that I take for granted because I've had a strong family support and people say well you know, you seem to be getting on with things, and I wonder why other people aren't. Well I used to when I was younger but then of course when you see a lot more you realise that, you know, gee I have had a really strong supportive family and was lucky. So now I see that as having been a strong factor. Doug

One of the women interviewed became very involved with the [Organization], representing the organization overseas. She made some insightful comments regarding how disabled women are treated in New Zealand compared to other countries.

I think being a New Zealander, having seen people in other countries, I think we're just so fortunate because you know I've talked to women overseas and over there you would definitely never marry a person who wasn't also disabled. Because it would be below a man who was able bodied – he would definitely not marry a disabled woman. She'd be useless.(...) In Asia that's certainly the case. Yeah and South East Asia, Pakistan and Thailand and those sorts of places, they are hidden away. Really hidden away.

5.4 Conclusions

Hammell (2007) undertook a meta-synthesis of qualitative research relating to QOL after SCI of which seven papers met the stated research criteria of rigor and relevance. The author concluded that there were 10 main concepts that contributed to or detracted from QOL after SCI. QOL was found to be impaired by (1) problems associated with impaired body; and by (2) a sense of loss. The experience of life worth living was enhanced by (3) meaningful relationships; (4) the assumption of responsibility for and an opportunity to have control over one's own life; and (5) the ability to engage in meaningful occupations and contribute. Also identified as being important to QOL was (6) environmental context, and (7) the development of new values and perspectives, by which (8) good and bad days were perceived as 'normal'; (9) the importance of reconstructing a positive sense of self worth and (10) self continuity.

When reviewing the interviews conducted with the 12 New Zealand SCI people, many of the concepts identified by Hammell were identified and discussed. The general findings from the 12 interviews presented in this chapter were consistent with those presented in the literature review in Chapter 2, and in Hammell's study yet there were some unique features that arose which were specific to this New Zealand sample. These issues were highlighted and taken into consideration when developing the questionnaire for the Phase 3 quantitative study. These issues are also discussed in more detail in Chapter 8 when discussing the overall research findings from all three phases of this study.

Ageing

It was recognised by a number of participants that as they grew older that they needed to be more flexible and adjust to circumstances as they arose. Some people had stopped driving, playing sport, and had started to use more assistive equipment and technology (e.g. electric wheelchairs, hoists). There was a recognition and acceptance that the body did not recover as quickly and that there was a need to be more careful about general health and when undertaking activities.

Spouses/partners were also becoming older and more physically compromised and unable to help as much which meant they needed to get other people to assist in the home. This was often a major adjustment in lifestyle and change in privacy which was difficult to accept for some. With people becoming more physically compromised it was recognised that more effort to maintain friendships was required. Maintaining part-time or full-time employment was more difficult, with fatigue especially a major consideration when deciding to reduce the

number of hours devoted to working. However the decision to continue working was often dictated by the financial impact. Many people talked about the need to develop patience and maintain a positive outlook on life.

Development of secondary conditions associated with time since injury

The participants had lived with SCI between 26 to 50 years. At the time many of these people had their SCI – in the 1960s and early 1970s – surviving the initial SCI was regarded a medical challenge, especially for tetraplegics. The first specialised SCI medical unit started at Christchurch Hospital in 1965 consisting of four beds. Living with SCI was initially very difficult, especially coming to terms with urinary and bowel incontinence. The majority of participants indicated that they had lived for a considerable amount of time following their injury with relatively stable health, periodically interrupted with short periods of ill-health often directly related to their SCI (e.g. urinary tract infections). In recent years, as they had grown older, they had started to develop a variety of secondary conditions which in some cases had severely affected their health. This had required people to monitor their general health and well-being much more closely than previously, especially in relation to skin care, bladder and bowel management; and shoulder and musculoskeletal issues. The development of secondary conditions did not appear to be recognised by the health professionals and there was a strong desire to have better access to SCI specialist advice and reassessment. The five paraplegics had fewer health issues than the seven tetraplegics. These research findings reflect those described in Chapter 3, where people with SCI seem to have a stable period of health between 20 to 25 years, before related secondary conditions start to develop. Also there is a clear indication that tetraplegics with higher neurological levels tend to experience more ill-health than paraplegics and people with incomplete SCI.

Changes in community environment and attitudes

Going home from the security of the hospital environment was seen as a very stressful time. Many people were discharged from hospital to a home environment that did not cater for SCI, especially if they required the use of a wheelchair. Overcoming such obstacles required considerable determination, imagination, and initiative on the behalf of the SCI person and their families or support people, including the wider community to rally around and offer both physical and financial assistance. Those participants who were pre-ACC, received no or minimal funding from the Government. The majority of public buildings and facilities were often not wheelchair accessible. Some of the people interviewed had taken leading roles in

promoting the rights of the disabled people and working towards to a more inclusive society; as described in Chapter 2. Disabled people coming together and becoming politically active at a local and national level eventually led to local bylaws and government legislation (e.g. *Human Rights Act 1993*) being introduced which ensured appropriate access to buildings and a much more inclusive society. With this increased accessibility, SCI people in wheelchairs were seen in the community more frequently and community attitudes gradually changed to become more accepting and inclusive. With a more accessible environment it was much easier for people with SCI to continue their education and find employment which was recognised as being important in improving self-esteem and financial security. This was particularly relevant for those people with SCI who were injured pre-ACC.

Quality of life

The majority had maintained good relationships and social interaction within the community. However, there was acceptance that it was different from what had existed before their SCI with a common comment being, “you find out who your true friends are”. It was recognised that relationships with family and friends were more important with increasing age. Deterioration in health and becoming more disabled with the development of secondary conditions had negatively affected QOL. Some people were finding such health deterioration difficult to accept. However, there was general recognition that improvement in technology, medical knowledge and treatment including the development of new medications had made major improvements in people's overall QOL.

Differences between ACC and Ministry of Health/Ministry of Social Development

ACC was established on the 1 April 1974. People's relationship with ACC was mixed, ranging from, “terrible” to “positive”. The relationship varied at different times over the years when there were major changes in government or internal ACC policy changes as well as personnel changes especially in regards to individual case managers. A common issue was the lack of information about entitlements and rights under the *Accident Compensation Act 1972*.

Those people who were pre-ACC felt considerably disadvantaged compared to those under ACC. For example, those under ACC were able to qualify for ERC which is 80% of their pre-injury taxable income. Regardless of their level of SCI, those people not on ACC either worked or applied to receive a disability allowance (unless they were 65 years or older at which time they receive the New Zealand Superannuation). The people who had their SCI before the existence of ACC had their care and equipment paid for by the Ministry of Health

and social support by the Ministry of Social Development, which replaced the Ministry of Social Welfare. In some cases people had their SCI before there was assistance available from the Ministry of Social Welfare which required them to be innovative and determined to overcome major obstacles. There was general strong feeling among those injured prior to the establishment of ACC that it was extremely unjust that ACC did not retrospectively recognise and accept their injuries.

Concluding comment

The Phase 1 qualitative research was undertaken to gain an understanding of the common issues confronting ageing SCI people in New Zealand and assist with the development of a questionnaire in Phase 3, the quantitative research. Such issues included the general implications of ageing with SCI, the development of secondary conditions, QOL of people as they grew older and the impact of the different funding criteria and policies between ACC and Ministry of Health and/or Ministry of Social Development. The next chapter describes how a database was developed to serve as a platform to undertake Phase 3 and quantify these issues.

Chapter 6: Phase 2 - Development of the research database

6.1 Introduction

Fundamental to any population or sample survey is the establishment of a reliable sampling frame. Thus before proceeding to develop a quantitative research proposal (Phase 3) it was necessary to identify people in New Zealand ageing with SCI (Phase 2). This required examining a variety of database sources within New Zealand to gain an understanding of the population information available, its format, and its reliability. Prior to this investigation, no national database or knowledge source was available that provided this information. Until this database or knowledge source was established and understood it was not possible to instigate Phase 3 of the study.

6.2 Methods

The key objective of Phase 2 was to identify people within New Zealand ageing with SCI. The methods used to achieve this were wide consultation with key stakeholders such as senior administrative and medical personnel at both spinal units, ACC, the NZST and the Association of Spinal Concerns (TASC), identification of existing databases, and the establishment of a format and reliability of the information they contained.

There were a variety of organizations within New Zealand that held various forms of information about people with spinal cord injuries. Preliminary fact-finding discussions were undertaken with the NZST, ASRU and BSU and TASC. The NZST, based in the Allan Bean Centre Burwood Hospital, Christchurch, is a nationwide consumer focused charitable trust that provides a variety of support services for spinal cord impaired people. It works in close association with staff from both spinal units concentrating on providing post discharge support and assistance e.g. information, vocational advice, peer support.

The ASRU, administered by the CMDHB and based in South Auckland, is responsible for providing rehabilitation services to people who incur a spinal cord injury and live north of a line from New Plymouth across to Hastings; see Figure 6.1. The BSU, administered by the CDHB and based in Christchurch, is responsible for providing acute and rehabilitative care for those people with SCI who live south of this New Plymouth across to Hastings line.



Figure 6.1 Admission boundary areas between the Auckland Spinal Rehabilitation Unit and Burwood Spinal Unit

(Supplied by Liz Oliver Service Manager BSU 2012)

TASC is a consumer led non-profit organization based at the ASRU which concentrates on providing a ‘buddy support’ system for those with a spinal cord injury in the Auckland area (<http://www.tasc.org.nz/>). The NZST’s Kaleidoscope database is a working database used by its vocational assessment team. When the Kaleidoscope database was developed in 2003 it was based on a pre-existing database that had been built in 2000 for a separate research project into the causes of SCI, funded by a grant from the New Zealand Racing Board. The NZST employed a person on a short-term contract to put the database together. The project ceased at the end of 2000 due to the NZST not being able to secure further funding for it to continue. The database developed in 2000 had a comprehensive record of all admissions to

the BSU and ASRU obtained from their Patient Information Management Systems (PIMS). Due to the database not being maintained a gap exists in records between 2000 and 2003. From 2003 onwards data were only captured for inpatients that were enrolled in the Kaleidoscope vocational programme (i.e. a relatively small subset of the total number of actual inpatients during that time).

The other sources of information are held by the ASRU, BSU and TASC. TASC had indicated that it would not allow direct access to its database. However, the organization was very supportive of the research and indicated that it would assist the researcher to contact a number of long-term SCI people in the Auckland area. It was accepted that there would be some overlapping of information from the different sources which would need to be addressed. These organizations were also asked for their advice on ways of making contact with people who were not on these four databases. It was a possibility that a person could incur a SCI and never be admitted to a specialised spinal unit, but rather be treated and discharged from a local general hospital. Suggestions included making contact through word-of-mouth, and organizational network magazines. TASC worked with the ASRU to supply additional names of people not identified on the CMDHB's PIMS.

To prepare for a possible survey of the population of interest, when looking at the information held by the NZST, BSU and the ASRU it was anticipated the minimum information that would be available would be a person's name, contact details, NHI number, date and type of injury, gender, age, and neurological level of injury.

6.3 Ethics

Prior to this investigation, no national database or knowledge source was readily available that provided information for people residing in New Zealand ageing with SCI. To be able to undertake an ethically reliable process to identify potentially contactable subjects it was important that key stakeholders, such as senior personnel from the NZST and both spinal units, were consulted when the process was being developed and carried out. This involved obtaining individual Multi-ethics Committee (MEC) locality assessment approvals from each organization. The number of ageing spinal cord injured people identified who met the subject criteria was an important factor as it would influence how the research proposal would be developed for Phase 3, the quantitative research project. There was no recruitment for research at this time. The information on the databases was kept secure by the people who had assisted with its preparation at the BSU and ASRU. To formally proceed with investigating

the information on the various databases and obtain appropriate research access to this information, it was necessary to submit a separate MEC application. After consultation with stakeholders, an MEC application was submitted and approved (Appendix 4) in mid-September 2009 (MEC/09/06/061).

6.4 Subject Criteria

Included were all people residing in New Zealand with SCI that had occurred before 1 January 1990. People who had their SCI outside of New Zealand before 1 January 1990 and now reside here were included in the study. People identified as being deceased or residing outside New Zealand were excluded. As highlighted in the results of the qualitative investigation and consistent with that described in Chapter 3, the literature review, there is evidence to suggest that people experience a maintenance phase over the first 20 or so years before starting to experience complications due to their SCI (Adkins, 2004; Capoor & Stein, 2005; McColl et al., 2003). Therefore it was decided to concentrate on identifying people for whom the onset of SCI was more than 20 years ago.

6.5 Setting and Process

In October 2009 the NZST's Kaleidoscope database was reviewed with the assistance of the Trust's CEO, Mr Andrew Hall. Over 1,400 people were identified on that database as having incurred a SCI before 1 January 1990. This number of potential participants was substantially larger than that anticipated. However, much of the information on the Kaleidoscope database had not been consistently updated since 2000, due to the inability to secure on-going funding to employ someone to maintain and keep the information on the database correct and accurate. The information identified on the Kaleidoscope database was transferred on to a Microsoft Excel spreadsheet and separated into patients that had been at some stage either admitted to the BSU based in Christchurch or the ASRU based in South Auckland. It was recognised that there may be people with a SCI living in New Zealand who had not been transferred and admitted to either spinal unit. These people could have been treated at the local hospital, especially if the SCI occurred in the 1960s before the spinal units existed. Due to the potentially large size of the population identified in the NZST's Kaleidoscope database, it was decided to concentrate on refining this database of approximately 1,400 people. This strategy was considered advantageous as the database clearly identified which spinal unit a person had been admitted to and enabled further checking and verification of the database information. Discussions were held with senior personnel from the two spinal units to

establish the best way to ensure the refinement and accuracy of the two spreadsheet databases. The process of checking and refining the data took place in November and December 2009.

Figure 6.2 shows the process involved in the development of the two databases of people with a SCI before 1 January 1990 based on admission to either the ARSU or BSU.

As part of the MEC locality assessment application undertaken for each DHB, the researcher sought and was granted temporary approval to work with DHB staff and information for the duration of the project.

At the BSU a temporarily employed clerical person, supervised by the Unit's Research Nurse, was contracted to identify and update details of those people admitted to the unit who had incurred their injury or condition before 1 January 1990. The following process was used:

1. The Kaleidoscope database spreadsheet was used as a starting point. After referring to the unit's 'deaths book', deceased individuals were removed from the research project spreadsheet database. The 'deaths book' was a handwritten book which had been in use since the mid-1960s which recorded details of individuals who were known to have died. In recent years the book had ceased to be used, however it was referred to as it identified people who were recorded as being deceased before the CDHB's PIMS came into existence.
2. Individual details were then checked on the CDHB's PIMS. Individuals identified as not being on the initial 'Kaleidoscope' database were added to the spreadsheet database. Those people recorded as being deceased or residing overseas were removed from the spreadsheet database. As the PIMS contact details were considered to have been more recently updated these details were used to update the spreadsheet database.
3. As a double check, the people listed on the spreadsheet database had their contact details from the PIMS compared with their telephone number and address in Telecom's "White Pages". It was found that of the 574 people, 159 (28%) had contact details that matched their contact details on the PIMS. The other 413 people did not have their contact details in Telecom's "White Pages". With the wide use of mobile telephones and with there now being more than one telecommunication company, many people no longer have their contact details in the Telecom "White Pages". It was decided to use the contact details on the PIMS.

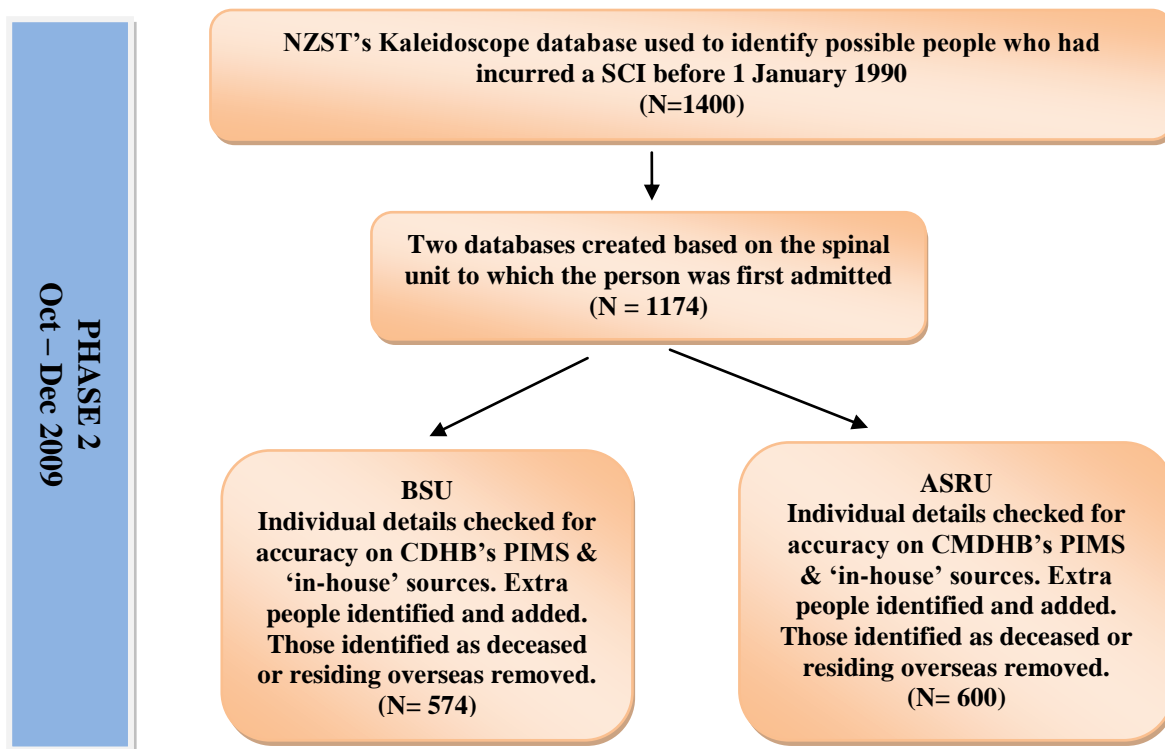


Figure 6.2 Developing two databases of people with a SCI before 1 January 1990 based on admission to either the Auckland Spinal Rehabilitation Unit or Burwood Spinal Unit

At the ASRU, its Administration Co-ordinator was contracted to identify those people who had been admitted to the unit who had incurred their injury or condition before 1 January 1990. She carried out the following process:

1. Individuals identified as being deceased on the ASRU's 'R' drive patient folders were removed from the spreadsheet database. The 'R' drive was an old computer record database no longer in use which recorded basic patient details.
2. Patient admissions from the ASRU log book dated from 1987 to 1989 were collated and any duplicated information was deleted. People that were identified as being deceased were also deleted.
3. Individual patient information and contact details were compared with the CMDHB's PIMS to ensure that individual contact details were updated and correct and any potential additional people were included.

4. Due to the relatively small number of people at the BSU who had corresponding contact details on the CDHB's PIMS and Telecom's "White Pages", it was decided not to proceed with this process at ASRU.

There was considerable discussion with senior personnel at the two spinal units about the high number of individual contact details on the CDHB's PIMS that did not match contact details in Telecom's "White Pages". An option discussed was to seek MEC approval to run the two databases through the national PIMS, through the Ministry of Health. The PIMS is meant to be updated annually, therefore recording more recent contact details. However, after discussion with personnel at the spinal units and thesis supervisors, it was considered this may not necessarily increase the validity of the research database for Phase 3. For instance, the substantially increased time delay in the development of the research database would itself cause issues, as would the access, consent and merging of the various additional component information sources. As part of the submission to the MEC and its subsequent approval, this was explicitly recognised, as was the need for the included database information to be reviewed and updated. The most appropriate way forward was to use the information and contact details that were on the DHBs' PIMS. The two spinal units would then contact people listed on the databases to request their consent to pass their contact details onto the researcher. This process was adopted and is outlined in more detail in the methods description of Phase 3, Chapter 7.

6.6 Results

By the end of December 2009, the initial 1400 people on the NZST's "Kaleidoscope" database had been refined to 1,185 people located on two databases, based on whether the person had been admitted to the ASRU or the BSU. Individuals who were known to be deceased or residing overseas had been eliminated and additional people identified on the DHBs' PIMS included. People who had their injury outside New Zealand before 1 January 1990 and now reside here were included in the study. Of the potential number of individuals with SCI incurred before 1 January 1990 verified through the PIMS (a total of 1,174 people), 600 had been through the ASRU and 574 through the BSU. Over the time that the databases were being finalised it was discovered a further nine people had died.

The two databases recorded the following information for each individual:

1. NHI number;
2. Contact address with postal code;

3. Telephone number if available;
4. Gender;
5. Date of birth;
6. Date of injury;
7. Neurological level of injury including whether it was complete or incomplete;
8. How the injury or condition happened, e.g. motor vehicle accident;
9. Form of mobility, e.g. manual wheelchair;
10. Last admission date to the spinal unit; and
11. Spinal unit.

The individual databases were retained by the relevant spinal unit on behalf of the researcher, as it was recognised there was an ethical issue regarding the sensitivity of the researcher having access to confidential health information about individuals (which, at this stage, the researcher did not have formal consent to use). The process developed to obtain formal individual consent from participants is outlined in Chapter 7 as part as Phase 3.

6.7 Conclusions

At the beginning of investigation of the various potential databases, it was unknown how many people there were residing in New Zealand, ageing with SCI. Until this was established and understood it was not possible to design the quantitative part of the doctoral research study.

It was decided to concentrate on identifying people who were ageing with SCI that they had incurred before 1 January 1990. People with SCI appear to start developing complications around or after twenty years of living with their injury or condition (Adkins, 2004; Capoor & Stein, 2005; McColl et al., 2003). The initial 1,400 people identified on the NZST's "Kaleidoscope" database was refined to 1,174 people located on two databases based on whether the person had been admitted to the ASRU (N=600) or the BSU (N=574) at some stage with SCI. This was after eliminating individuals who were deceased or residing overseas and the inclusion of additional people identified on the DHBs' PIMS. Limitations associated with identifying people through the PIMS include the fact that the contact details such as name, address and telephone number were only as reliable as the last time the person came in contact with a hospital using the Ministry of Health's PIMS. If someone had not been

in hospital for many years or had shifted from the address logged in the PIMS then the person would not be able to be contacted. It was initially considered that it might be possible to identify the number of people who had died since the onset of SCI and the reasons for this death. However, senior personnel in the spinal units indicated that this information had not been systematically recorded and was not available in any reliable form. The personnel in the two spinal units were surprised that so many people had been identified as having SCI before 1 January 1990. With a larger number of people available to be contacted than originally anticipated, it made the issue of ageing with SCI all the more poignant to the researcher and all those people involved in the research study. The larger than anticipated number of people available to be contacted also increased the likelihood of obtaining a sample of a sufficient size and power to detect important patterns and associations in a quantitative study. The researcher was able to write with confidence the research proposal for Phase 3, the quantitative part of the study, and make an application to the MEC.

Chapter 7: Phase 3 - National cross-sectional survey of people with long-term spinal cord injury

7.1 Introduction

When this research began it was clear that there was little knowledge or understanding about the demographic profile of people ageing with SCI in New Zealand, including basic details about the number of people ageing with SCI, their injury status, neurological levels, ethnicity, gender, age, marital status, time since injury, education, employment or living circumstances. A focused literature review of research on ageing with SCI highlighted that after approximately 20 years post injury, people ageing with SCI can start to develop secondary health conditions. The literature review also identified relevant issues such as demographic and injury related details, development of secondary conditions related to time since injury, health status, social interaction, life satisfaction and perceived QOL and identifying current social and environmental barriers that influence QOL.

Phase 1 of the research provided some insights into living with SCI in New Zealand and drew attention to the important issue of differences in funding between the Ministry of Health and ACC. To quantify these and other important features of this population, a national database of people living with SCI incurred before 1 January 1990 was established (Phase 2), and provided the basis for Phase 3 investigations. The aim of Phase 3 is to survey a national cohort of ageing SCI people to address the important issues identified in the literature and Phase 1 of the research, and to provide a basis for a selective comparative analysis with non-disabled people. The comparative analysis draws on information obtained from Massey University's 2006 study into Health Work and Retirement (HWR), an age appropriate New Zealand-based national sample and information from the 2006 New Zealand Census and the Health of New Zealand Adults 2011/12 survey.

Four research objectives were developed:

1. What is the socio-demographic and injury profile of people ageing with SCI in New Zealand?
2. What are the employment, living status, health and well-being, physical activity, and social support characteristics of people ageing with SCI in New Zealand?

3. What are the relationships of socio-demographic and injury profiles, employment, living status, health and well-being, physical activity, and social support characteristics with time since incurring the original SCI?
4. What are the differences in employment, living status, health and well-being, physical activity, and social support profiles of people ageing with SCI in New Zealand between those people who received support from the Ministry of Health and ACC?

Employing a cross-sectional design, using information from the two updated databases held at the ARSU and BSU developed in Phase 2 in 2009, a national quantitative survey was developed and administered in 2011 to explore the demographic, health, social and living circumstances and QOL of people ageing with SCI before 1 January 1990.

7.2 Methods

7.2.1 Study Design

A cross-sectional national survey of people sustaining a SCI prior to 1 January 1990.

7.2.2 Population

The population consisted of people currently residing in New Zealand, with a long-term SCI who had been identified in Phase 2 (see Chapter 6). Inclusion criteria included: incurring SCI before 1 January 1990 which has affected a person's mobility or neurology; having been admitted at some stage to either the ASRU or BSU; and having a NHI number and current contact details on the Ministry of Health's PIMS. Exclusion criteria included: not currently residing in New Zealand; being resident in New Zealand but non-English speaking; or being deceased. These exclusion criteria were established to ensure that there was a cross-sectional nation-wide study of current living individuals who were able to complete the questionnaire. The doctoral thesis had limited financial resources and it was impracticable to recruit and have on-call nationwide translators for the likely minimal number of non-English speaking participants.

7.2.3 Questionnaire

A complete copy of the survey appears in Appendix 5. The questionnaire was designed to be distributed electronically to participants, with the option for a paper-based version. The survey questionnaire was designed to obtain baseline information about people ageing with SCI, such as general demographic and health-related QOL information and living

circumstance information. The questionnaire was developed using a variety of sources, but most heavily drew from: [1] previous research studies on people with ageing with SCI (Chapter 3); [2] the exploratory qualitative interviews undertaken by the researcher (Chapter 5); and [3] Massey University's 2006 Health, Work and Retirement (HWR) postal questionnaire.

The HWR Study was established to identify the influences on health and well-being in later midlife (55 to 70 years) that laid the basis for community participation and health in later life. The study is an ongoing project which over time aims to collect information on the physical and mental health of older workers and retirees, catalogue various work and retirement factors, and record socioeconomic and demographic status as people make the transition from work to retirement. To date there have been four waves of postal survey data collection (2006, 2008, 2010 and 2012). Participants in the HWR were randomly selected from the New Zealand electoral rolls, with the inclusion criterion being that they were aged between 55-70 years in 2006. Because the age range was similar to the age of the range established in Phase 2, it was considered that the 2006 baseline HWR postal survey would potentially offer useful comparison of results with the current study. The HWR survey has been accessed through the study's website (<http://hwr.massey.ac.nz/>). One of the doctoral supervisors (Dr Sally Keeling), who is also a named investigator with the HWR study, facilitated the formal establishment of this study with the HWR research team at Massey University. The HWR team responded very positively to the collaboration with the ageing with SCI study and assisted by providing the questionnaire, research methodology and rationale behind the development of their questionnaire and research process.

Table 7.1 provides a summary of the questionnaire's section headings and topics, the measures employed the sources of the questions and the link to particular questions. The instructions section of the questionnaire gave participants information on how to complete the questionnaire with an example. The questionnaire was made up of the following sections:

Background information

The background questions were designed to collect information about people's demographic details which included living and social circumstances and details about circumstances relating to the individual's SCI. Background Questions 1 to 4 relating to age, gender, relationship status and ethnicity were selected from the Individual Form used in the 2006 New Zealand Census of Population and Dwellings. Questions 13 to 16 related to the composition

of the household for which the participant was financially responsible. Questions 5 to 12 drew on information learned in the qualitative research phase and included questions on the individual's SCI and the circumstances under which it was incurred, sources of financial support and the type of services received. Questions 17 to 33 which were derived from the HWR study related to where people lived, educational qualifications, employment, income of participants and other household members, superannuation and social aspects of living standards.

Health and disability

The purpose of this section was to gain a better understanding of the health profile of people ageing with SCI especially in relation to general health status, QOL and the use of alcohol, tobacco and health services. Questions 1 to 11 use the Short-Form 36 version 2 (SF-36v2) developed by Dr John Ware in 1996 (McDowell, 2006), with some minor changes being made to reflect terminology in New Zealand and also assist the SCI sample to better understand some questions. Some of these changes had been adopted by the HWR study. The modifications were reviewed and found suitable by QualityMetrics (Kopeck, 2012), the organization that licences the use of the SF-36v2. The SF-36v2 is a multi-purpose health survey made up of 36 questions divided into eight profiles of functional health and well-being as well as psychometrically-based physical and mental health summary measures and a preference base health utility index. It is a generic measure, as opposed to one that targets a specific age, disease, or treatment group. With rare exceptions, published reliability statistics have exceeded the minimum standard of 0.70 recommended for the measures used in group comparisons in more than 25 studies. Reliability estimates for physical and mental a summary scores usually exceed 0.90 (Ware, 2012). The minor changes made were: In Question 3 the sentence "Does your *heath now limit you* in these activities?" was changed to read "Does your *health and/or disability now limit you* in these activities?", item g the words "*Walking more than one mile*" was changed to "*Walking more than 1km*", item h the words "*Walking several hundred yards*" were changed to "*Walking several blocks*" and item i the words "*Walking one hundred yards*" were changed to "*Walking one block*". The original three items in question 5 in the original SF-36v2 were replaced with the four items from question 4. Item c in question 5 in the SF-36v2 has the wording, "Did work or activities *less carefully than usual*". The present study used the wording in item c, "*Were limited*" in the kind of work or other activities" and item d has the wording, "Had *difficulty* performing the work or other activities (for example, it took extra effort)".

Question 12 focused on asking participants if they had any of 19 listed health problems. Questions 13 to 16 used the World Health Organization's Alcohol Use Disorder Identification Test (AUDIT-C) to establish how much and how often participants have a drink containing alcohol. It consists of three AUDIT items on consumption frequency, quantity and bingeing (Bush et al., 1998). The AUDIT-C is recommended for use in primary health care settings worldwide and is a well-known established screener for alcohol use disorders and risk of drinking. It has performed slightly better in screening dependence among women than men (Dawson et al., 2005). Questions 17 to 22 asked participants' about how much and the type of health services (e.g. general practitioners, community services, hospital services etc) they had used over the previous 12 months. Questions 23 to 25 asked questions about participants tobacco use.

Physical activity

The physical activity questions related to activities done by people as part of their everyday lives, such as activities at work, in the house and garden, to get from one place to another or spare time activities for recreation, exercise and sport. The questions were derived from the NZFPAQ-Short Form developed by Sport and Recreation New Zealand (McLean & Tobias, 2004) and slightly modified to better suit SCI participants (e.g. 'pushing a wheelchair or briskly walking but only a little harder e.g. getting from one place to another').

Table 7.1 Summary of the questionnaire's section headings, measures used and question source

Section & Sub-Topic	Measure Used	Source	Questions
1. Instructions			
2. Background Information			
Demographic/Social data	Census/demographic	NZ Census (2006)	1-4, 13-16
SCI related information	Qualitative study	PhD Study	5-12
Employment and income	HWR (2006)	HWR (2006)	17-33
3. Health and Disability			
Health-related quality of life	SF36V2 ^a	SF36V2 Scoring Manual (Ware et al 2002)	1-11
Chronic health conditions	Diagnosed health problems	HWR (2006)	12
Alcohol consumption	AUDIT-C ^b	World Health Organization (2001)	13-16
Health service use	Health care utilization (MoH)	Health Care Utilisation (HWR 2006)	17-22
Tobacco use	HWR (2006)	HWR (2006)	23-25
4. Physical Activity			
Brisk walking/moderate/vigorous	NZPAQ Short form ^c	SPARC (2004) ^d	1-2
Physical activity over 6 months	Stage of exercise adoption	SPARC (2004)	3
5. Social Support			
Volunteerism	HWR (2006)	HWR (2006)	1
Social networks	The Network Assessment Instrument	Wenger (1994), HWR (2006)	2-4
Social support levels	The Social Provision Scale	Russell & Catrona (1984)	5
Caregiving levels	Australian Women's Health study	HWR (2006)	6-10
Isolation and trust levels	Ministry of Social Development (2005)	HWR (2006)	11-12
Forms of contact	HWR (2006)	Wenger (1994), HWR (2006)	13-14

^a Short Form 36 version 2; ^b Alcohol Use Disorder Identification Test; ^c New Zealand Physical Activity Questionnaire; ^d Sport and Recreation New Zealand

Social support

Research has indicated that an important aspect of having positive QOL is maintaining active participation in the community and participating in enjoyable activities as well as having the feeling of contributing to society to fulfil one's potential. This also involves having good social support systems (Geyh et al., 2012; McColl et al., 2004; Sakakibara et al., 2012). The questions in Section 5 replicate the 2006 HWR questions on social support. They focus on peoples' social interaction in society, maintaining social networks and supports as well as their beliefs about oneself and family and whānau. Question 1 in this section asked about how much time participants contributed to volunteer activities. Questions 2 to 4 related to social networks and were derived from Wenger's Social Networks Assessment Scale (Stephens & Noone, 2008; Wenger, 1997) with changes being made to suit the New Zealand culture and environment. Question 5 used Russell and Cutrona's (1984) Social Provision Scale (SPS) (Cutrona & Russell, 1987; Mancini & Blieszner, 1992) which asked participants to what extent they agreed with 24 statements (ranked using a four item Likert scale) covering attachment, social integration, reassurance of worth, reliable alliance, guidance, and opportunity for nurturance. The SPS originates from a concept (Weiss, 1974) suggesting that relationship functions encompass both social networks and the consequences of relational deficits. It appears especially appropriate for helping to explain the connection between social interaction and psychological well-being as people proceed through life and experience changes in close relationships due to changing life events. Questions 6 to 10 related to care giving to others with questions 11 and 12 relating to trust and isolation. Questions 13 and 14 related to forms of contact such as attending religious meetings, community/neighbourhood or social groups, such as clubs, lectures or similar activities. Question 14 asked participants about the type of contact they had with people (e.g. telephone, e-mail).

Question 15 the final question to the survey, asked participants if they had any other comments they would like to make. People were thanked for taking time to complete the survey.

7.2.4 Piloting the questionnaire

A pilot study was undertaken with a convenience sample of ten participants who were each sent a questionnaire (five by e-mail and five by post). When all questionnaires were returned, contact was made with each participant either by e-mail or telephone seeking feedback about

the questionnaire and the survey process, and enquiring how improvements could be made. Nine people found the questionnaire interesting and easy to complete, with participants completing the questionnaire in approximately 30 minutes. Two people commented that they would have liked the questionnaire to have been more specific about SCI matters. The researcher explained that the rationale behind developing the questionnaire was to obtain general demographic and health-related QOL information, rather than concentrate on specific spinal cord issues.

As a result of the pilot feedback, specific changes made to the questionnaire were: the on-line questionnaire settings were corrected to enable exiting the questionnaire to be easier; for Section 2 Background Information the on-line settings for question 27 about superannuation were changed to allow more than one box to be ticked; in Section 3 Health & Disability spelling mistakes in questions 1 and 11 were corrected; in Section 4 Physical Activity question 1 contained two typographical errors which were corrected by replacing 'and' to 'at' and replacing 'putting' for 'pushing'; and an open-ended question asking if people have any further comments was added to the end of the questionnaire.

The modified questionnaire was sent to the MEC with a covering letter outlining the changes to the questionnaire. After the MEC approved the final changes (MEC/11/01/002) (Appendix 6) the research project proceeded in April 2011 with sending the questionnaire to all consenting participants. As the changes to the questionnaire in the pilot study were very minor, the questionnaire responses from the 10 trial participants were also included in the study's research data set.

7.2.5 Procedure

Recruitment

To give initial publicity to the research study an article was written for the May 2011 issue of the Spinal Network News magazine (Appendix 7), which is a quarterly magazine published by the NZST. The magazine is circulated to over 600 people who have SCI or have an interest in the Trust's activities. The article was published just prior to the beginning of the recruitment process. The article noted that the researcher had a personal interest in the research having a spinal cord injury for 36 years himself and also personally encountering physical complications due to ageing. It mentioned that 12 people with SCI injured 25 years or longer had been interviewed and the findings supported overseas studies indicating that

there was not only significant physical deterioration and complications from the injury itself, but that the group was affected by the normal ageing processes that affect the wider community, such as heart disease and other chronic diseases. The article also reported that with the approval of the MEC, and help from the NZST, BSU and ASRU about 1,000 people had been identified from whom consent would be sought for them to be contacted to take part in a survey on ageing with SCI. It was noted that this was a unique chance for those with spinal conditions to let the Government and health providers know what the issues were, and people were urged to take part in the scientific survey with national coverage. Contact details were given where people could make contact with the researcher.

The national database developed in Phase 2 was the basis for recruitment. The two spinal units agreed to send to all people on the database an envelope by post enclosing a covering letter of support signed by a senior medical consultant (see Appendix 8), a Summary Information Sheet (see Appendix 9) which explained the purpose and specific aims of the research, what was involved in completing the questionnaire, what would happen to the information obtained from the questionnaire and a contact point in the event that a person required more information or had any queries, a Consent Form (see Appendix 9) and a return pre-paid envelope self-addressed to the person assisting the researcher at the relevant spinal unit. The Consent Form had a declaration indicating that the person signing had read the Summary Information Sheet, understood that they were free to withdraw at any time and, if there were any queries or concerns, that they could either contact the researcher or his supervisor or alternatively an independent Health and Disability advocate (contact details provided). The consenting person gave their contact details, including an e-mail address (if applicable) and an indication of preference as to how they wanted to complete the questionnaire, on-line using a computer to enter a secure on-line survey website or have a questionnaire sent to them by post. The consent form had a separate page for those declining to complete the questionnaire where the person signed and dated the form indicating they did not consent to have their contact details passed on to the researcher. The form giving or declining consent was returned to the relevant spinal unit by post in the enclosed self-addressed pre-paid envelope.

For those consenting, contact details were verified, including telephone number and e-mail address, if available. To ensure the accuracy of individual contact details and current living status of potential participants, administrative staff from the two spinal units checked the

information stored on the PIMS. Potential participants, who were recorded as being deceased or may have moved overseas since the initial database was completed in 2009, were removed from the database.

The spinal units then passed to the researcher the names and contact details of those who had consented to take part in the study. If people returned the Consent Form indicating that they did not wish to take part in the study, this was noted on the original database. Four weeks after the survey information packs were sent out, those subjects who had not replied were identified, their contact details checked, and follow-up contact made either by post or telephone by personnel from the two spinal units. The aim was to verify that they had received the initial information and to ask them again whether they would like to take part in the survey or not. If they did wish to take part, another information pack was sent.

Survey process

The questionnaire was sent either by post or by email with instructions on how to complete the questionnaire via a secure website. When a posted completed questionnaire was returned the information in the questionnaire was manually loaded onto the Survey Monkey website to ensure that all the participants were compiled into one single file. Every individual questionnaire had a unique code number that linked the person to the original database of consenting individuals to ensure that the questionnaire was confirmed as having been completed and returned. The database of consenting individuals identified whether the questionnaire had been sent by post or completed by computer via a secure website. The research database had all personal identifying information removed and individuals included within the sample who identified only by their study code number.

Statistical analysis

The raw data downloaded from Survey Monkey, was coded and prepared in Microsoft's Excel spreadsheet and consistency checks were employed. Out of range or missing data were checked, and where possible, corrected. The data was then imported into the statistical programme SPSS (IBM SPSS, 2011) for analysis.

Descriptive statistical analysis consisted of summary statistics, frequency distributions, scatterplots and correlation analysis. Lowess curves, non-parametric mean-estimator functions, were employed to visually ascertain patterns or trends within scatterplots before statistical analysis. Where possible, and if appropriate, comparison was made with

information from the 2006 HWR sample, 2006 Census data, Health of New Zealand Adults 2011/12 survey and the New Zealand General Social Survey 2010 (Ministry of Health, 2012; Statistics New Zealand, 2007a, 2011; Stephens & Noone, 2008). Statistical comparisons were made using Student's t-test or ANOVA, where appropriate, for continuous variables and Fisher's exact test for categorical variables.

Logistic and simple linear regression analysis was undertaken for dependent variables, which included: injury level, rated standard of living, rated satisfaction with standard of living, and rated income meeting everyday needs. In-line with the Phase 3 research questions, independent variables investigated included: age; years since injury; gender; marital status; level of injury (tetraplegic, paraplegic, walking); non-ACC (people not covered by ACC) vs ACC; region – earthquake (Christchurch, Waimakariri and Selwyn districts) vs non earthquake (all other districts in New Zealand); employment status; and income. Crude and adjusted models were employed. Given the sample size, a two-stage approach was employed for the derivation of adjusted analyses – whereby all significant bivariable factors were included into the adjusted model without stepwise selection. The significance level for all statistical tests was set at $\alpha = .05$, unless explicitly stated otherwise.

7.3 Results

7.3.1 Participant recruitment

Figure 7.1 depicts the participant flow diagram for Phase 3.

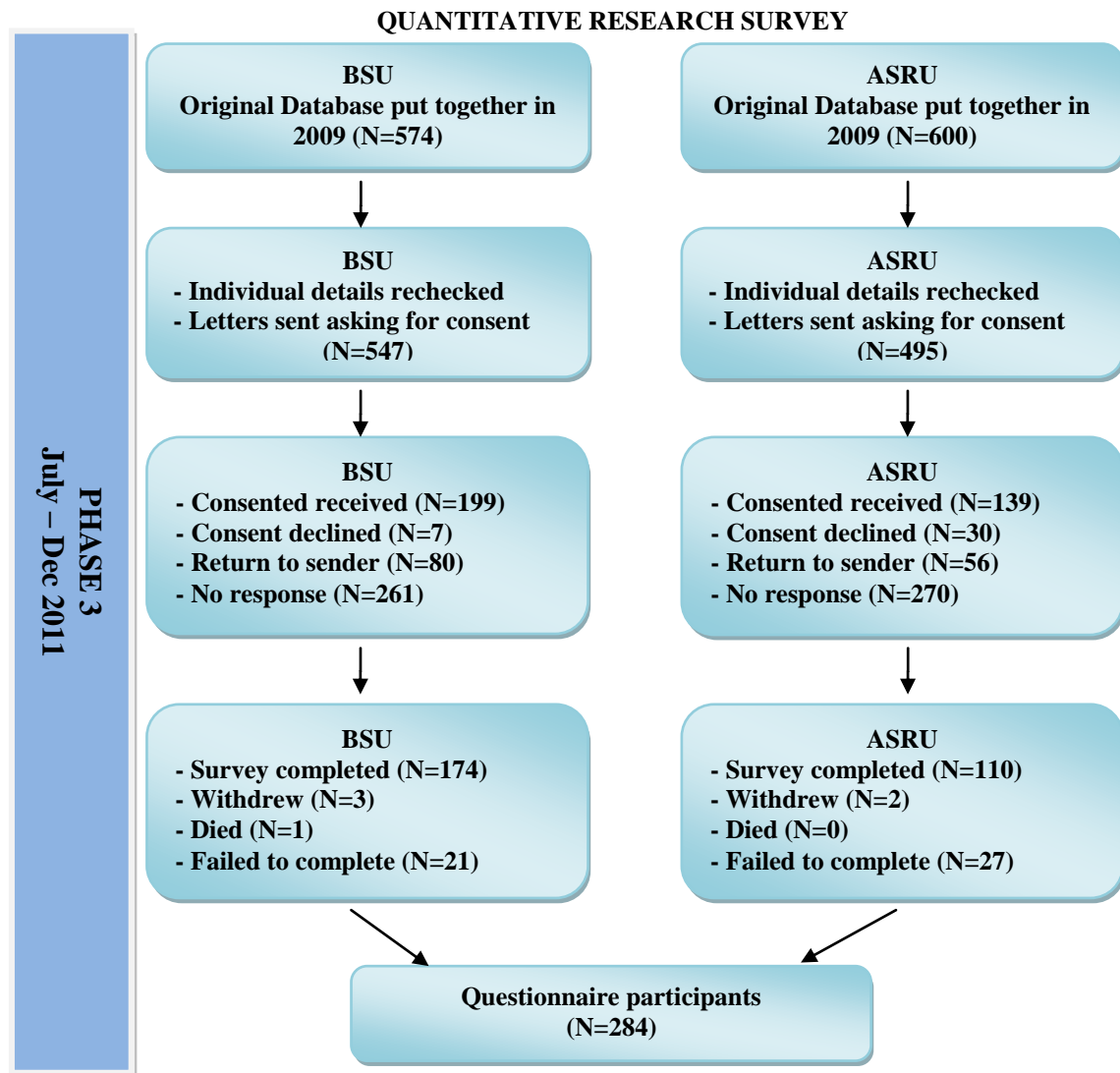


Figure 7.1 Participant flow diagram for Phase 3

As the actual process of recruitment differed slightly at the BSU and ASRU the process of recruitment at each unit is described separately.

BSU recruitment

The database that was compiled in association with the BSU in December 2009 (Phase 2) was reviewed in early June 2011 by the unit's Research Nurse who coordinated the sending out of information and consent forms. Individual contact details were rechecked on the Ministry of Health's PIMS. This rechecking was conducted at the same time as the sending out of consent forms. Unfortunately this differed from the suggested research protocol. The Research Nurse scheduled this doctoral research project around her usual work obligations, therefore the time she was able to devote to the project was intermittent and resulted in the recruitment of people taking longer than originally anticipated. Of the 574 people on the BSU database, 20 were recorded as being deceased, six were living overseas and one person was the researcher. Removing these people reduced the number eligible to 547. From mid-June to the end of the August 2011 letters were mailed to all 547 people. Enclosed in the sent envelope was an individually addressed covering letter signed by Mr Raj Singhal Medical Consultant (a member of the senior medical team at the BSU), the information sheet, consent form and a prepaid return envelope. In addition two people were recruited through the article that was published in the NZST's May 2011 issue of the Spinal Network Magazine. These individuals were not recorded on the original database. The reason for this is unclear. It possibly could relate to their original SCI being coded incorrectly or differently. However, once their details were able to be verified on the Ministry of Health's PIMS they were added to the BSU database.

From the letters sent, 199 people replied consenting to participate in the study, seven replied declining the invitation to participate, 80 letters were returned due to the person no longer living at that address, and from 261 there was no response. Questionnaires were sent either by mail or on-line to all 199 consenting people. Overall, 174 completed and returned their questionnaire, three withdrew after receiving the questionnaire, one died, and 21 failed to complete and return their questionnaires. For those not responding, the researcher made two contacts (via e-mail or telephone) encouraging the individuals to complete and return the questionnaire.

ASRU recruitment

A similar but subtly different process was adopted for the ASRU participant recruitment from that described above for the BSU. Specifically, the database put together with the ASRU in

December 2009 (Phase 2) was reviewed by the Administration Officer in late July 2011 by re-checking individual details on the Ministry of Health's PIMS. Of the 600 people on the database, 52 were not found on the PIMS; 55 were recorded as being deceased and five were living overseas. This reduced the number of eligible people to 495. During late July and early August 2011 letters were mailed to all 495 people. Enclosed in the sent envelope was a covering letter signed by Dr Cynthia Bennett Medical Consultant (a member of the senior medical team at ASRU), the information sheet, consent form and a self-addressed prepaid return envelope.

From the letters sent, 133 people replied consenting to the study, 56 letters were returned due to the person no longer living at the mailed address, and from 306 there was no response. The Administration Officer made follow-up phone calls to 166 people, resulting in 29 people agreeing to have the letter with the information sheet and consent form re-sent to them. By 19 October 2011 a further six people had returned a consent form. It was agreed with the ASRU Administration Officer that any further effort to make contact would result in little benefit. Of the 139 people who consented to take part in the study, 110 completed and returned the questionnaire, two people withdrew after receiving the questionnaire, and 27 failed to complete and return their questionnaires. Again, for those not responding, the researcher made two contacts (via e-mail or telephone) encouraging the individuals to complete and return the questionnaire.

7.3.2 Participant profile

To determine the socio-demographic and injury profile of people ageing with SCI in New Zealand, and any differences in how people age depending on whether they have SCI or not.

This section covers the socio-demographic and injury profile of people ageing with SCI in New Zealand and where possible comparison has been made with the HWR sample, 2006 Census data and the Health of New Zealand Adults 2011/12 survey.

Socio-demographic information

In total, 284 people participated in the Phase 3 study with 146 (51.4%) completing the questionnaire by computer via a secure website and 138 (48.6%) by post. Table 7.2 summarises the key demographic characteristics of the participants. Overall, 225 (79.2%) were male, the mean age was 57 years (range: 28, 83 years), 233 (84.4%) self-reported as

being of Pakeha/New Zealander of European descent. Of the participants, 169 (61.2%) were in a marriage, de facto or civil union relationship. The mean age when injured was 25.7 years (range: 2, 57 years); and so the mean time that people had lived with their injury was 31.6 years (range: 21, 59 years). This compares with the 2006 Census which indicated Europeans and 'others' made up 77% of the total population, Māori comprised 15%, Pacific people 7% and a broad Asian ethnic group 10% of the total population (Statistics New Zealand, 2006).

Table 7.2 Demographic profile of participants (n=284)

Demographics	Mean	(SD)
<i>Age (years)</i>	57.2	(10.0)
<i>Age at injury (years)</i>	25.7	(9.8)
<i>Time since injury (years)</i>	31.6	(7.5)
	n	(%)
<i>Gender</i>		
Male	225	(79.2)
Female	59	(20.8)
<i>Ethnicity</i>^a		
European/Pakeha	233	(84.4)
Māori	33	(12.0)
Chinese	5	(1.8)
Other	5	(1.8)
<i>Marital status</i>^a		
Married/de facto or civil union	169	(61.2)
Never married	51	(18.5)
Separated	48	(17.4)
Widowed	8	(2.9)

^a 8(2.8%) values missing.

Injury characteristics

The distribution of injury characteristics of the participants appears in Table 7.3. Ninety-eight (34.6%) participants described themselves as being tetraplegic, 112 (39.4%) paraplegic and 72 (25.4%) as walking. With respect to neurological level, there were considerable differences between complete and incomplete classifications. For example 34.6% of people indicated that they had a complete cervical injury, with 11.0% indicating that they had an incomplete cervical injury. Those people with a complete injury are more likely to have sustained complete paralysis below their level of injury, whereas those people indicating that they had sustained an incomplete injury potentially have feeling or movement (e.g. walking) below

their level of injury. This explains variations in reported mobility with 49.2% of the sample indicating that they used a manual wheelchair, 8.6% of people used an electric wheelchair, and 9% used an electric wheelchair in combination with a manual wheelchair. A further 11.7% walked with an aid and 3.1% walked with an aid and also used a manual wheelchair. A total of 18.4% indicated that they walked with no assistance.

In terms of causes of the injury, motor vehicle and motorbike accidents combined to make up 50% of the participants. Sporting accidents were 13.9%, followed by 8.4% incurring their injury in a fall. Only 11 (4%) people indicated that their spinal cord injury was related to a medical condition.

Education profile

Table 7.4 presents participants' secondary school and tertiary qualifications. Of the 271 people who responded, 87 (32.1%) had no school qualifications, 69 (25.5%) had school certificate and 115 (42.4%) had 6th form certificate or higher. There were 132 (49.3%) people with a tertiary qualification. Seventy-eight (29.6%) people had a trade certificate or diploma/certificate and 54 (19.7%) indicated they had a university degree or postgraduate qualifications. The 2006 Census data indicated that 22.4% of the New Zealand population 15 years and over had no school qualifications and 35.8% of people had a post-school education qualification. The HWR sample had 31.5% with no school qualifications and 41.9% of people had a post-school education qualification (Towers & Noone, 2007). The proportion of people with no qualifications was no different between the study sample and the HWR sample ($p=0.85$, two-sample test of proportions).

Table 7.3 Injury characteristics of participants (n=284)

Characteristic	n	(%)
<i>SCI</i> ^a		
Tetraplegic	98	(34.6)
Paraplegic	112	(39.4)
Walking	72	(25.4)
<i>Neurological level</i> ^b		
C1-C7 Complete	93	(35.4)
C1-C7 Incomplete	29	(11.0)
T1-T12 Complete	85	(32.3)
T1-T12 Incomplete	19	(7.2)
L1-L5 Complete	22	(8.4)
L1-L5 Incomplete	11	(4.2)
S1 Complete	1	(0.4)
S1 Incomplete	3	(1.2)
<i>Mobility</i> ^c		
Electric wheelchair	22	(8.6)
Electric/manual wheelchair	23	(9.0)
Manual wheelchair	126	(49.2)
Walking with the use of an aid	30	(11.7)
Manual wheelchair/walking with an aid	8	(3.1)
Walking	47	(18.4)
<i>Type of accident or condition</i> ^d		
Motor-vehicle	103	(37.6)
Motorbike	34	(12.4)
Sporting	38	(13.9)
Fall	23	(8.4)
Diving	19	(6.9)
Falling object	11	(4.0)
Medical misadventure	11	(4.0)
Medical condition	11	(4.0)
Work injury	10	(3.6)
Aviation	9	(3.3)
Other	10	(3.6)

^a2 (0.7%) values missing; ^b21 (7.4%) values missing; ^c28 (9.9%) values missing; ^d10 (3.5%) values missing.

Table 7.4 Educational qualifications of participants

Qualification	n	(%)
<i>Secondary education</i> ^a		
No school qualifications	87	(32.1)
School Certificate	69	(25.5)
6 th Form Certificate	25	(9.2)
University Entrance and higher	87	(32.1)
Overseas secondary school qualification	3	(1.1)
<i>Tertiary qualification</i> ^b		
None	133	(50.6)
Trade certificate	38	(14.4)
Diploma or certificate	40	(15.2)
University degree	33	(12.5)
University post-graduate degree	19	(7.2)

^a13 (4.6%) values missing; ^b21 (7.4%) values missing

Employment profile

Table 7.5 presents declared occupations classified using the Australian and New Zealand Standard Classifications of Occupations (ANZSCOSv1.1) used by the New Zealand Department of Statistics (Pink & Bascand, 2009). A notable feature of this table is that 165 (58.1%) participants did not respond to this question. Here, non-response is comprised of those who did not have an occupation and those who declined to answer; an important distinction that unfortunately could not be disentangled.

Of the 119 (41.9%) people who did respond, the largest group was 54 (19.0%) people classified as professional, followed by 25 (8.8%) people working as managers and 14 (5.0%) people working as technicians and trades workers. In comparison, the 2006 Census data indicated 19% of the general population were professionals with 17% being classified as managers and 12% technicians and trade workers. The HWR sample had 26% as professionals, 22% as managers and 11% as technicians and trade workers. Few people in the participant sample (1.8%) were working as machinery operators, drivers or labourers reflecting the realities of living with SCI and having physical limitations. The 2006 Census data indicated 17% of the population worked as machinery operators and drivers or labourers and the HWR sample had 12% working as machinery operators and drivers or labourers (Towers & Noone, 2007).

With only 41.9% of the total number of people indicating their employment status, it places limitations on the validity of further statistical comparisons with this variable. As such, comparisons are likely to contain significant inherent biases which would affect the generalisability of any results.

Table 7.5 Participant occupations compared with the HWR sample and 2006 Census

<i>Occupational group</i> ^a	Participants		HWR	2006 Census
	n	(%)	(%)	(%)
Chose not to response or did not have an occupation	165	(58.1)		
Managers	25	(8.8)	(22.0)	(17.0)
Professionals	54	(19.0)	(26.0)	(19.0)
Technicians and trade workers	14	(5.0)	(11.0)	(12.0)
Community and personal services workers	7	(2.5)	(6.0)	(3.0)
Clerical and administrative workers	9	(3.2)	(15.0)	(12.0)
Sales workers	5	(1.8)	(12.0)	(15.0)
Machinery operators and drivers	4	(1.4)	(5.0)	(6.0)
Labourers	1	(0.4)	(7.0)	(11.0)

^aANZSCO1.1 classifications

Participants' current employment situation was compared with their preferred situation; see Table 7.6. Of the 270 participants who responded to the question on their employment status, 120 (44%) indicated they were employed full-time or part-time including self-employment. A total of 83 (31%) people were either on the invalid benefit (10%) or ACC (21%). A further 52 (19%) indicated they were retired or not in paid work. When looking at the 200 people who reported their preferred employment situation, the percentages were considerably different. Here 64 (32%) wished to be part-time, compared with 35 (13%) currently part-time, 3 (2%) would prefer to be on an invalid benefit, compared to 27 (10%) who were on such a benefit, and 21 (11%) would prefer to be on ACC compared to 56 (21%) who were. When looking at those who would prefer to be working part-time, only 33% actually were working part-time, 19% were on an invalid benefit, 19% were on ACC, and 12% were working full-time. Of those receiving ACC, 46% declared that they would prefer receiving ACC, 29% would prefer part-time employment, and 17% would prefer full-time employment. Of those on the invalid's benefit, none preferred to be receiving this, but 60% wished to be in part-time employment. These finding suggests the many participants' employment desires are not being met.

Table 7.6 Current employment situation of participants compared to their preferred situation

	Current ^a	Preferred ^b
	n (%)	n (%)
Full- time paid employment, including self-employment	85 (31.5)	68 (34.0)
Part-time paid employment including self-employment	35 (13.0)	64 (32.0)
Retired, no paid work	52 (19.3)	38 (19.0)
Full-time homemaker	8 (3.0)	4 (2.0)
Part-time or full-time student	4 (1.4)	2 (1.0)
Unemployed and seeking work	3 (1.1)	0 (0.0)
Invalid's benefit	27 (10.0)	3 (1.5)
ACC	56 (20.7)	21 (10.5)

^a 14 (4.9%) missing; ^b 85(29.9%) values missing;

Income sources

Table 7.7 presents sources of income and the type of superannuation scheme participants were enrolled with. Sources of income were complex and varied. Of the 272 participants, 95 (35%) received income from full-time or part-time paid employment or self-employment. A total of 103 (37.9%) received income from ACC with 58 (21.3%) also having income from other sources. Forty-four (16.2%) participants received New Zealand Superannuation (NZS) or veterans' pension with 18 (6.6%) having other income sources. There were 25 (9.2%) participants who received income solely from the invalid benefit (7.4%) or other disability type government benefits (1.8%).

One hundred and two participants (36%) indicated they had some form of superannuation scheme, with 67 (65.7%) of these indicating they were with the Government's KiwiSaver. A further 14 (13.7%) indicated they were in the KiwiSaver scheme as well as another superannuation scheme. Twenty one (20.6%) people indicated they were in a private or work-related superannuation scheme.

Table 7.7 Sources of income and the type of superannuation scheme participants were enrolled in

	n	(%)
<i>Sources of income for those declaring an occupational group ^a</i>		
Wages, salary, paid by the employer	34	(12.5)
Self-employment or business I own and work in	10	(3.7)
Regular payments from ACC	45	(16.5)
New Zealand Superannuation or veterans pension	26	(9.6)
Invalid's benefit	20	(7.4)
Other government benefits	5	(1.8)
ACC plus other sources of income	58	(21.3)
Wages etc plus other sources of income	35	(12.9)
Self-employment plus other sources of income	16	(5.9)
New Zealand superannuation plus other sources of income	18	(6.6)
Interest, dividends, rent and other sources of income	4	(1.5)
Another household member	1	(0.4)
<i>Superannuation ^b</i>		
KiwiSaver	67	(65.7)
KiwiSaver plus another employment/superannuation scheme	14	(13.7)
Other employment retirement or superannuation scheme	21	(20.6)

^a12 (4.2%) values missing; ^b182 (64.0%) values missing

The distribution of reported participant income compared to the HWR sample and 2006 Census data are presented in Table 7.8. Of the 258 participants who estimated their income, 158 (61.2%) indicated their annual income was less than \$40,000. The HWR data indicated 62.0% (Towers & Noone, 2007) and the 2006 Census data indicated 67.4% (Statistics New Zealand, 2007a) of the population received income of \$40,000 or less. Comparing the proportion of people with an annual income \$40,000 or less there was no statistical difference between the study sample and the HWR sample ($p=0.25$, two-sample test of proportions).

Household and living circumstances

Table 7.9 outlines key household circumstances including the size of town or city that a person lives in, the composition of the household, and the number of people financially dependent on the participant. Of the 273 people who responded, 145 (53.1%) lived in an urban area with a population of 30,000 or more. Conversely, 38 (14.1%) people indicated they lived in a rural area outside a town or city boundaries.

Table 7.8 **Reported participant income compared to HWR and 2006 Census income data**

Income group	Participants ^a		HWR	2006 Census ^b
	n	(%)	(%)	(%)
Under \$20,000	66	(25.6)	(33.2)	(42.8)
\$20,001 to \$40,000	92	(35.7)	(29.0)	(29.7)
\$40,001 to \$70,000	58	(22.5)	(25.0)	(19.3)
\$70,001 to \$100,000	26	(10.1)	(7.0)	(4.4)
Over \$100,001	16	(6.2)	(6.0)	(3.7)

^a26 (9.1%) values missing; ^b 320,892 (10.1%) not stated

Of the 266 people who responded, 61 (22.9%) indicated they lived alone which is a similar percentage (23%) of people in the 2006 Census data that indicated they lived in a one-person household (Statistics New Zealand, 2006). If it can be assumed that the Census measured proportion of living alone numbers can be generalised to people with SCI, then there is no difference in the proportions between the study sample and the 2006 Census ($p = 0.99$, exact binomial test). A total of 185 (69.5%) participants indicated they lived with other family members, with 41.0% indicating they lived solely with a spouse or partner and 19.2% indicating they lived in a family environment with more than one family member. One hundred and twenty-three participants indicated they had household members financially dependent on them. The number of people financially dependent varied ranging from only one dependent person (58% of participants) to six dependents (2% of participants). Comparison with the HWR sample would have been constructive unfortunately the information available was not in a format to enable appropriate comparison to be made.

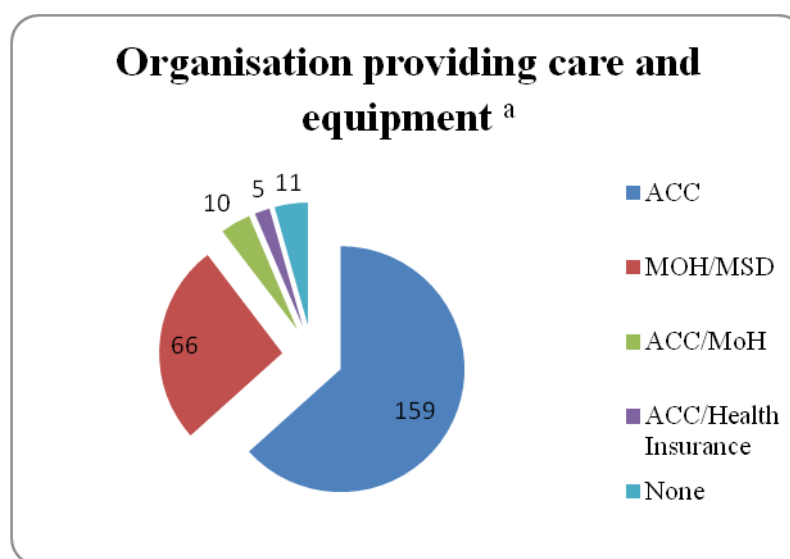
Provision of care and support

Figure 7.2 indicates the type of Organization that participants indicated was paying for their care and/or equipment. Of the 251 people who responded to this question 159 (63.3%) indicated they received financial support from ACC, with 66 (26.3%) people receiving support from government agencies such as the Ministry of Health or Ministry of Social Development. Ten (4.0%) participants indicated that they received support both from ACC and the Ministry of Health. This joint ACC and Ministry of Health support occurs when someone receives financial support for care and equipment from the Ministry of Health and subsequently has an accident which also enables them to qualify for support from ACC.

Table 7.9 Household living circumstances of participants

	n	(%)
<i>Living environment^a</i>		
Main urban area - 30,000 and more people	145	(53.1)
Secondary urban area between 10,000 - 29,999 people	39	(14.3)
Minor Urban area between 1000 - 10,000 people	26	(9.5)
Rural area between 300 - 1000 people	25	(9.2)
Rural area - outside a town or city boundaries	38	(13.9)
<i>People living in the same household^b</i>		
Husband/wife/partner	109	(41.0)
More than one family member	51	(19.2)
Son(s) and/or daughter(s)	14	(5.3)
Mother and/or father	9	(3.4)
Flatmate(s)	15	(5.6)
Live alone	61	(22.9)
Other	7	(2.7)

^a11 (3.9%) values missing; ^b18 (6.3%) values missing;



^a33 (11.6%) values missing.

Figure 7.2 Financial support for care and equipment

Table 7.10 presents the pattern of care for participants. Of the 247 (87%) participants who indicated they received home help and attendant care, 111 (44.9%) received home help, 53 (21.5%) received attendant care and 83 (33.6%) received both home help and attendant care. A total of 149 (60.3%) participants indicated that their care was organised from within the

household either by a spouse/partner (26.3%), themselves (24.7%), family member (7.3%) or flatmate (2.0%). This compares with 98 (39.7%) participants who indicated their home help and/or attendant care was organised by an organization including a nursing agency or person outside the home. To sum up, the majority of people are taking responsibility within their domestic setting for organising care and assistance.

Table 7.10 Organising the provision of home help and attendant care (n=247)

Organiser	Home help		Attendant Care		Both		Total	
	n	(%)	n	(%)	n	(%)	n	(%)
Spouse/partner	34	(11.9)	13	(4.6)	18	(6.3)	65	(26.3)
Carers organised by myself	22	(7.7)	13	(4.6)	26	(9.1)	61	(24.7)
Family member/whanau	7	(2.5)	5	(1.7)	6	(2.1)	18	(7.3)
Flatmate(s)	4	(1.4)	1	(0.3)	0	(0.0)	5	(2.0)
Carers organised by organization/person	29	(10.2)	12	(4.2)	14	(4.9)	55	(22.3)
Nursing Agency	15	(5.3)	9	(3.2)	19	(6.7)	43	(17.4)
Total	111	(44.9)	53	(21.5)	83	(33.6)	247	(100)

Sample representativeness

In an attempt to understand the magnitude of any differential recruitment patterns, the demographic profile of participants and non-participants (those who were eligible but did not complete the questionnaire) are presented and compared in Table 7.11. Although there were statistically significant differences in age and time since injury between participants and non-participants, on a practical level the mean differences were relatively small and unlikely to substantially bias any pursuant results. This, coupled with the similarity in age at injury and gender profiles of the participants and non-participants, suggests that the sample is likely to be ‘broadly representative’ but that some important non-sampling biases may exist. However the sample captured a diverse group of people and the findings are likely to be generally representative of people living with SCI for over 20 years in New Zealand.

Table 7.11 Comparison of key demographic variables between participants (n=284) and non-participants (n= 614)

Demographic	Participants (n=284)		Non-participants (n=614) ^a		P-value ^d
	Mean	(SD)	Mean	(SD)	
Age (years)	57.3	(10.0)	54.5 ^b	(11.7)	< 0.001
Age at injury (years)	25.7	(9.8)	25.8 ^c	(11.2)	0.90
Time since injury (years)	31.6	(7.5)	28.9 ^c	(6.2)	< 0.001
Gender	n	(%)	n	(%)	0.55
Male	225	(79.2)	473	(77.0)	
Female	59	(20.8)	141	(23.0)	

^a 8 people became deceased between July to Oct 2011 and those with mail returned to sender were not included;

^b 14 (2.2%) values missing; ^c 22 (3.6%) values missing; ^d Student's t-test for comparison of means and Fisher's exact test for categorical comparisons.

7.3.3 Living status of participants

To determine the living status, of people ageing with SCI in New Zealand in relation to key characteristics of age, years since injury, gender, region affected by the Canterbury earthquakes, income from ACC and relationship status.

This section shows the results of the living status of people ageing with SCI in New Zealand. It covers participant injury level, reported standard of living, satisfaction with standard of living and whether income met participants' current needs. Analysis was undertaken relating the reported living status variables to key participant characteristics of age, years since injury, gender, regions affected by Canterbury earthquakes, income from ACC and relationship status.

Selected characteristics relevant to living status

Key characteristics such as age, years since injury, gender, regions affected by the Canterbury earthquakes (Christchurch, Selwyn and Waimakariri districts), income from ACC and relationship status were chosen for further analysis. In Table 7.12 these characteristics are tabulated according whether participants described themselves as tetraplegic, paraplegic or walking. Eighty-nine (90.8%) of the 98 tetraplegics were male compared to the overall sample average of 79.4%. In order to investigate the impact of Canterbury earthquakes on people's responses, regional location was identified. Of the 282 people reporting their disability characteristic, 56 (20%) indicated they lived in the Christchurch, Selwyn or Waimakariri

districts, which were recognised as being the districts most affected by the 2010-11 earthquakes and aftershocks. There was a higher percentage of tetraplegics (52.6%) receiving income from ACC compared to paraplegics (34.3%) and walkers (20.6%) which is consistent with the research literature that indicates the more severe the SCI, the less likely the person is to be working. With regard to those participants who were in a marital, de facto or civil union relationship, the percentage of tetraplegics was lower (50%) compared to paraplegics (63%) and walkers (74.3%).

Table 7.12 Participant injury level compared with selected characteristics (n=282)

	Tetraplegic (n=98)		Paraplegic (n=112)		Walkers (n=72)		P-value*
	Mean	(SD)	Mean	(SD)	Mean	(SD)	
<i>Age</i>	55.1	(8.8)	58.3	(10.6)	58.7	(10.4)	
<i>Years since injury</i>	31.8	(7.6)	33.7	(8.0)	28.4	(5.5)	
<i>Gender</i>	n	(%)	n	(%)	n	(%)	
Male	89	(90.8)	79	(70.5)	56	(77.8)	0.001
Female	9	(9.2)	33	(29.5)	16	(22.2)	
<i>Region</i>							
Christchurch, Selwyn, Waimakariri	16	(16.3)	20	(17.9)	20	(27.8)	0.161
Other areas	82	(83.7)	92	(82.1)	52	(72.7)	
<i>ACC^a</i>							
ACC	51	(52.6)	36	(34.3)	14	(20.6)	<0.001
Non-ACC	46	(47.4)	69	(65.7)	54	(79.4)	
<i>Marital Status^b</i>							
Married/de facto/civil union	48	(50.0)	68	(63.0)	52	(74.3)	0.006
Never married/separated/widowed	48	(50.0)	40	(37.0)	18	(25.7)	

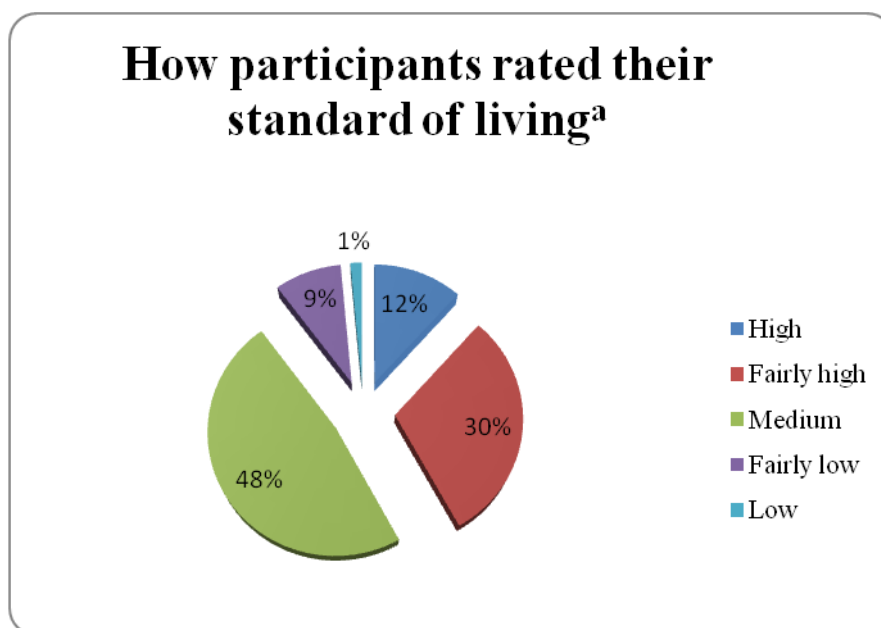
^a12 (4.3%) missing values; ^b8 (2.8%) missing values

*P-values calculated using one-way ANOVA test

Rated standard of living

Living status consisted of participant rated standard of living, participant rated satisfaction with current standard of living and whether participants considered their total income meets their everyday needs for such things as accommodation, food, clothing and other necessities. Participants rated their standard of living using a five point Likert scale 'high', 'fairly high', 'medium', 'fairly low' and 'low'.

Figure 7.3 depicts how participants rated their standard of living, with 42% rating it fairly high or high.



^a10 (3.5%) values missing

Figure 7.3 How participants rated their standard of living

Rated standard of living was associated with the selected participant characteristics of age, years since injury, gender, region, ACC versus non-ACC and marital status. Employment was not included as it was considered there were likely to be significant inherent biases due to the large number of ill-defined responses which could affect the generalisability of the results.

In Table 7.13, when comparing the selected participant characteristics with the categories of standard of living, only injury level was found to be significant ($p < 0.001$). A higher number of tetraplegics rated their standard of living high compared to paraplegics and walkers; and then, in contrast, a higher number of paraplegics and walkers rated, their standard of living moderate compared to tetraplegics. Gender, age, years since injury, gender, region, receiving ACC and marital status were not significantly related to participant rated standard of living. As the number of participants that rated their standard of living 'fairly low' and 'low' was small, the two categories were combined for statistical analyses.

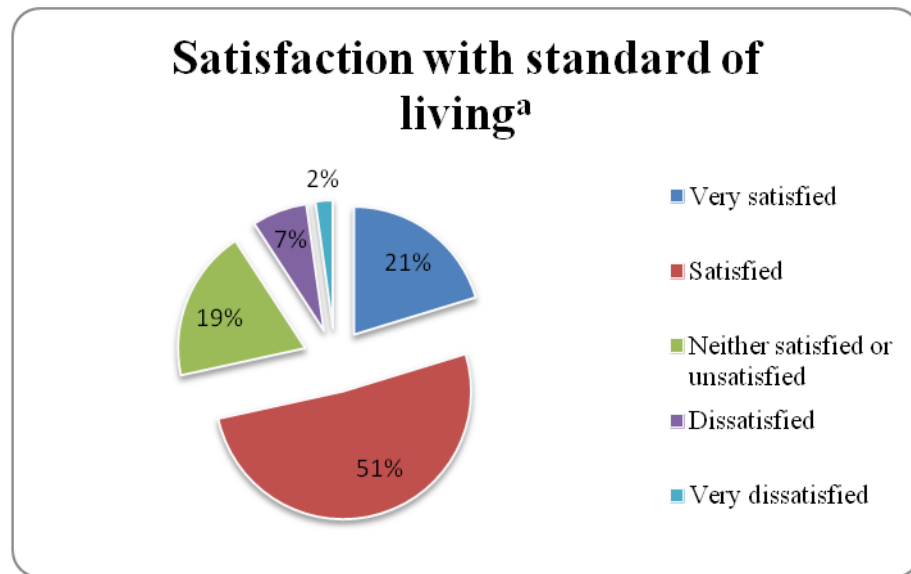
Table 7.13 Relationship of participant rated standard of living to selected participant characteristics

	Standard of Living								P*
	High		Fairly High		Medium		Fairly low/Low		
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	
<i>Age</i>	54.4	(7.1)	57.1	(10.4)	58.3	(10.9)	55.1	(8.5)	0.159
<i>Year since injury</i>	32.3	(7.2)	31.6	(7.2)	31.6	(7.8)	31.1	(7.9)	0.954
<i>Gender</i>	n	(%)	N	(%)	n	(%)	N	(%)	
Male	29	(13.3)	68	(31.2)	100	(45.9)	21	(9.6)	0.267
Female	3	(5.4)	15	(26.8)	31	(55.4)	7	(12.5)	
<i>Injury Level</i>									
Tetraplegic	20	(20.8)	32	(33.3)	32	(33.3)	12	(12.5)	< 0.001
Paraplegic	11	(10.4)	33	(31.1)	56	(52.8)	6	(5.7)	
Walker	1	(1.4)	18	(25.7)	41	(58.6)	10	(14.3)	
<i>Region</i>									
Christchurch	7	(13.0)	15	(27.8)	25	(46.3)	7	(13.0)	0.814
Other	25	(11.4)	68	(30.9)	106	(48.2)	21	(9.5)	
<i>ACC</i>									
ACC	13	(13.0)	27	(27.0)	48	(48.0)	12	(12.0)	0.727
Non-ACC	19	(11.2)	54	(32.0)	81	(47.9)	15	(8.9)	
<i>Marital Status</i>									
Married/de facto/civil union	20	(11.8)	57	(33.7)	84	(49.7)	8	(4.7)	0.002
Never married/separated/widowed	12	(11.5)	25	(24.0)	47	(45.2)	20	(19.2)	

* P-values are for Fisher's exact test, or one-way ANOVA tests, as appropriate.

Satisfaction with standard of living

Next, satisfaction with standard of living was elicited. Satisfaction was rated by using a five point Likert scale 'very satisfied', 'satisfied', 'neither satisfied nor dissatisfied', 'dissatisfied' and 'very dissatisfied'. Figure 7.4 depicts participant rated satisfaction with their standard of living. The majority (72%) indicated they were satisfied or very satisfied.



^a13 (4.6%) values missing

Figure 7.4 Participant rated satisfaction with standard of living

Satisfaction with standard of living was also associated with the selected participant characteristics. In Table 7.14 the participant characteristics of age, years since injury, gender, injury level, region, receiving ACC and marital status were found not to be of significance when compared with the reported categories of satisfaction with standard of living. Again, the number of participants that indicated they were ‘dissatisfied’ or ‘very dissatisfied’ was small, therefore these categories were combined for statistical analyses.

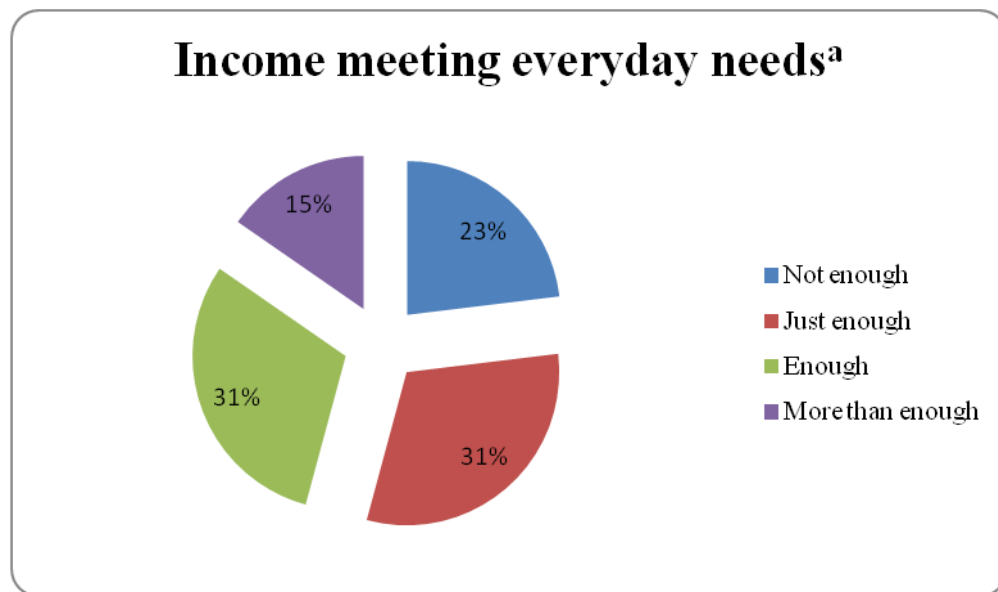
Table 7.14 Relationship of participant rated satisfaction with standard of living with selected participant characteristics

	Satisfaction with Standard of Living								P*
	Very satisfied		Satisfied		Neither		Dissatisfied/ Very dissatisfied		
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	
Age	55.7	8.4	58.5	10.8	56.8	11.0	53.6	8.6	0.089
Year since injury	31.0	(6.8)	32.0	(7.8)	31.9	(7.9)	30.6	(7.4)	0.740
	n	(%)	N	(%)	n	(%)	n	(%)	
Gender									
Male	45	(20.9)	111	(51.6)	41	(19.1)	18	(8.4)	0.768
Female	10	(17.9)	28	(50.0)	11	(19.6)	7	(12.5)	
Injury Level									
Tetraplegic	27	(28.1)	44	(45.8)	14	(14.6)	11	(11.5)	0.113
Paraplegic	20	(19.0)	53	(50.5)	25	(23.8)	7	(6.7)	
Walker	8	(11.8)	40	(58.8)	13	(19.1)	7	(10.3)	
Region									
Christchurch	13	(24.1)	24	(44.4)	11	(20.4)	6	(11.1)	0.681
Other	42	(19.4)	115	(53.0)	41	(18.9)	19	(8.8)	
ACC									
ACC	24	(24.2)	44	(44.4)	17	(17.2)	14	(14.1)	0.069
Non-ACC	29	(17.4)	94	(56.3)	33	(19.8)	11	(6.6)	
Marital Status									
Married/de facto/civil union	37	(22.2)	87	(52.1)	33	(19.8)	10	(6.0)	0.113
Never married/separated/widowed	17	(16.5)	52	(50.5)	19	(18.4)	15	(14.6)	

* P-values are for Fisher's exact test or one-way ANOVA tests, as appropriate.

Income meeting everyday needs

Finally, participants rated the extent to which total income met their everyday needs by rating on a four point Likert scale 'my income is not enough', 'my income is just enough', 'my income is enough' and 'my income is more than enough'. Figure 7.5 indicates whether participants rated whether their income met their everyday needs. Fifty four percent indicated that their income was just enough or not enough to meet their everyday needs.



^a11 (3.9%) values missing

Figure 7.5 Participants rating whether income meets every day needs

Table 7.15 reports that there is a significant relationship between age and needs met by income ($p=0.018$). Post hoc testing (using the Bonferroni method for multiple comparisons) indicated this was due to a significant difference in ages between those who stated they had enough vs not enough and those who had enough vs just enough ($p<0.05$). There was also a statistically significant association between marital status and needs met by income ($p=0.006$) with participants who are in a relationship more likely to be in the more than enough/enough categories than those participants not in a relationship. Participant characteristics of years since injury, gender, injury level, region, and receiving ACC were not significantly different over the categories of income meeting everyday needs.

Table 7.15 Relationship of participant rated income meeting everyday needs with selected participant characteristics

	Needs Met by Income								P*
	More than enough		Enough		Just enough		Not enough		
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Age	56.0	8.6	59.0	10.9	58.3	10.3	54.1	9.6	0.018
Year since injury	33.2	(7.5)	30.9	(7.3)	32.7	(8.0)	30.4	(7.1)	0.113
	n	(%)	N	(%)	n	(%)	n	(%)	
Gender									
Male	37	(17.1)	68	(31.3)	65	(30.0)	47	(21.7)	0.309
Female	5	(8.9)	15	(26.8)	20	(35.7)	16	(28.6)	
Injury Level									
Tetraplegic	18	(18.8)	30	(31.2)	26	(27.1)	22	(22.9)	0.180
Paraplegic	20	(18.9)	28	(26.4)	36	(34.0)	22	(20.8)	
Walker	4	(5.8)	24	(34.8)	23	(33.3)	18	(26.1)	
Region									
Christchurch	9	(17.0)	21	(39.6)	12	(22.6)	11	(20.8)	0.308
Other	33	(15.0)	62	(28.2)	73	(33.2)	52	(23.6)	
ACC									
ACC	16	(16.0)	33	(33.0)	27	(27.0)	24	(24.0)	0.854
Non-ACC	25	(14.9)	51	(30.4)	54	(32.1)	38	(22.6)	
Marital Status									
Married/de facto/civil union	31	(18.5)	55	(32.7)	50	(29.8)	32	(19.0)	0.056
Never married/separated/widowed	10	(9.6)	28	(26.9)	35	(33.7)	31	(29.8)	

* P-values are for Fisher's exact test or one-way ANOVA tests, as appropriate.

Relationship between rated standard of living, satisfaction with standard of living and with needs being met by current income

It might be expected that there is a degree of inter-dependence between participants' elicited responses to questions about rated standard of living, satisfaction with standard of living and with needs being met by current income. To ascertain this level of dependence, Spearman's correlations were estimated; with results presented in Table 7.16. From this table a moderate correlation can be observed between the three standard of living variables; participant rated standard of living, satisfaction with current standard of living, and whether participant needs were met by total income. However, the fact that each measure explained a sufficiently different component of the variability warranted separate investigations to capture conceptual and information variability.

Table 7.16 Correlation between variables rating standard of living, satisfaction with standard of living and needs being met by current income

Participant rated standard of living		
.656** (271)	Satisfaction with current standard of living	
.556** (273)	.525** (270)	Needs met by income

*Correlation is significant at the 0.01 level (2-tailed).

Crude and adjusted analysis of rated standard of living and with needs being met by current income

Tables 7.17 and 7.18 report the crude odds ratios for each of the predictor variables compared with participant rated standard of living and participant rated income meeting every day needs. In these analyses, age was treated as a tricotomous continuous variable defined by approximate tertiles: up to 50 years (29%), 51 to 60 years (37%), greater than 60 years (34%). For both dependent variables, being in a relationship increased the odds of a positive outcome, whilst being female decreased the odds of a positive outcome. For standard of living, injury level also significantly increased the odds of a positive outcome, with tetraplegics three times and paraplegics almost twice as likely to be in the positive outcome category as walkers.

When looking at the significant variables identified in crude analysis together, adjusted analyses showed no significant predictors for satisfaction with standard of living, therefore no table is presented. For standard of living the predictive variables entered into the model were: age, gender, injury level and marital status. The final model was derived at the third step and the OR for the significant predictors are reported in Table 7.17. Tetraplegics were almost four times and paraplegics twice as likely to rate standard of living high or fairly high compared to SCI people who indicated they were walking. Those who were in a relationship were twice as likely to rate standard of living high or fairly high compared to those not in a relationship.

Table 7.17 Odds ratio analysis of participant rated standard of living (high and fairly high) with participant characteristics

	Total N	High & Fairly High n (%)	Crude analysis* OR (95% CI)	Adjusted analysis* OR (95% CI)
Gender				
Female	56	18 (32.1)	0.6 (0.3, 1.1)	
Male	218	97 (44.5)	1.0 (reference)	
Injury Level				
Tetraplegic	96	52 (54.2)	3.1 (1.6, 6.1)	3.8 (1.9, 7.6)
Paraplegic	106	44 (41.5)	1.9 (1.0, 3.7)	2.0 (1.0, 3.9)
Walker	70	19 (27.1)	1.0 (reference)	1.0 (reference)
Marital Status				
Married/de facto/civil union	169	77 (45.6)	1.6 (0.9, 2.6)	1.9 (1.1, 3.3)
Never married/separated/widowed	104	37 (35.6)	1.0 (reference)	1.0 (reference)

* Adjusted for age.

For needs met by income the predictor variables entered into the model were: age (continuous), years since injury, gender, injury level and marital status. The final model was derived at step four and the significant predictors are reported in Table 7.18. Females were 50% less likely to consider their income more than enough or enough to meet their needs compared to males. With regard to marital status those in a relationship were almost twice as likely to consider their income was more than enough or enough to meet their needs compared to those people not in a relationship.

Table 7.18 Odds ratio analysis of participant rated income meeting everyday needs (more than enough and enough) with participant characteristics

	Total	More than enough/Enough	Crude analysis*	Adjusted analysis*
	N	n (%)	OR (95% CI)	OR (95% CI)
Gender				
Female	56	20 (35.7)	0.6 (0.3, 1.1)	0.5 (0.3, 1.0)
Male	217	105 (48.4)	1.0 (reference)	1.0 (reference)
Injury Level				
Tetraplegic	96	48 (50.0)	1.6 (0.9, 3.1)	
Paraplegic	106	48 (45.3)	1.2 (0.7, 2.3)	
Walker	69	28 (40.6)	1.0 (reference)	
Marital Status				
Married/de facto/civil union	168	86 (51.2)	1.7 (1.0, 2.9)	1.9 (1.1, 3.1)
Never married/separated/widowed	104	38 (36.5)	1.0 (reference)	1.0 (reference)

* Adjusted for age.

Note: A moderate correlation was observed between participants' age and years since injury ($r=0.41$); a correlation which is unlikely to cause important co-linearity issues within the adjusted analyses.

7.3.4 Reported participant health, social interaction and health service use

To determine the health and disability, physical activity, and social support characteristics of people ageing with SCI in New Zealand.

This section presents the results of the participants' health and well-being, social interaction and health service use. The health and well-being sub-heading presents the results of the SF-36v2 scores, reported health problems, alcohol consumption, smoking trends and physical activity. Social interaction covers the type of support and care provided to others, communication and relationship with family/whānau, and interaction and communication with other people. Health service use presents results of community health service use, General Practitioner (GP) usage and reported hospital admissions. Where possible, comparison has been made with information from the HWR sample, 2006 Census and the Health of New Zealand Adults 2011/12 survey.

Health and well-being

The SF-36v2 is a multi-purpose health survey made up of 36 questions divided into eight profiles of functional health and well-being as well as psychometrically-based physical and mental health summary measures. Table 7.19 compares the SF-36v2 mean scores of the SCI population with the Health, Work and Retirement (HWR) mean scores for the European population age group 55 to 69 years of age (Stephens et al., 2010). It was decided to compare the SCI population's SF-36v2 mean scores with the HWR's scores for the European population age group 55 to 69 years of age because the SCI population's average age was 57.2 years with 84.4% being European. All the SCI mean scores were substantially lower than the HWR mean scores, except for the mental component summary (MCS) scores. Because the 95% CIs do not overlap there remains a significant difference between the groups on the MCS scale with the SCI group having a significantly higher MCS score than the HWR (see Table 7.19). In general terms, the higher the SF-36v2 scores, the better the health status, the lower the score the worse the health status.

Table 7.19 **Reported SF-36v2 scores: SCI mean scores compared to HWR mean scores**

SF-36v2 Domains	SCI		HWR ⁱ	
	Mean	(CI 95%)	Mean	(CI 95%)
Physical functioning (PF)	29.1 ^a	(27.7, 30.4)	80.4	(79.3, 81.1)
Role physical (RP)	39.0 ^b	(37.6, 40.4)	82.4	(81.6, 83.1)
Bodily pain (BP)	42.2 ^c	(40.9, 43.4)	72.0	(71.2, 72.7)
General health (GH)	44.4 ^c	(43.0, 45.8)	72.0	(71.3, 72.6)
Vitality (VT)	47.3 ^d	(46.1, 48.5)	65.9	(65.3, 66.5)
Social functioning (SF)	43.8 ^e	(41.5, 44.2)	86.2	(85.3, 86.9)
Role emotion (RE)	44.7 ^f	(43.1, 46.4)	88.8	(88.2, 89.4)
Mental health (MH)	50.6 ^g	(49.4, 51.7)	81.4	(81.0, 82.0)
Physical component summary (PCS)	34.2 ^h	(33.0, 35.4)	50.2	(49.9, 50.5)
Mental component summary (MCS)	52.6 ^b	(51.3, 53.9)	50.5	(50.3, 50.8)

^a13(4.6%) values missing; ^b20(7.0%) values missing; ^c9(3.2%) values missing; ^d12(4.2%) values missing; ^e10(3.5%) values missing; ^f24(8.4%) values missing; ^g11(3.9%) values missing; ^h21(7.4%) values missing; ^{ij}N=3852 (source: Stephens et al., 2010)

In Table 7.20 the mean physical and mental component summary scores were partitioned by gender, marital status, level of injury, non-ACC versus ACC, region (earthquake vs non-earthquake affected) and employment status groupings and statistically compared. The physical component summary (PCS) mean score at its lowest indicates substantial limitations in self-care, physical, social, and role activities; severe bodily pain; frequent tiredness; and

health rated “poor”. At its highest, the score indicates no physical limitations, disabilities, or decrements in well-being; high energy level; and health regarded as being “excellent”. The mental component summary (MCS) mean score at its lowest indicates frequent psychological distress, substantial social and role disability due to emotional problems; and health generally rated “poor”. At its highest the score indicates frequent positive affect; absence of psychological distress and limitations in usual social/role activities due to emotional problems; and health rated “excellent”(Saris-Baglama et al., 2011). Within the mean MCS scores there were significant differences between employment status classifications ($p<0.001$). Those people who were not in a relationship and not working showed the lowest MCS mean scores. The mean PCS scores showed significant differences ($p<0.001$) within level of injury, non-ACC versus ACC and employment status variables. In regard to mean PCS significant scores, tetraplegics, those on ACC and those not working had the lowest PCS mean scores.

Table 7.20 SF-36v2 mean physical and mental component summary scores compared with independent variables

	Physical Component Summary Score			Mental Component Summary Score		
	Mean	(CI 95%)	P-value	Mean	(CI 95%)	P-value
Gender						
Male ^a	34.0	(32.6, 35.3)	0.466	52.6	(51.2, 54.2)	0.835
Female ^b	35.1	(32.2, 37.9)		52.9	(50.4, 55.5)	
Marital status						
Married/de facto/civil union ^c	35.1	(33.4, 36.8)	0.045	53.9	(52.3, 55.5)	0.020
Never married/separated/widowed ^d	32.7	(31.0, 34.3)		50.7	(48.3, 53.0)	
Level of Injury						
Tetraplegic ^d	30.5	(28.9, 32.2)	<0.001	51.8	(49.2, 54.5)	0.340
Paraplegic ^c	33.9	(32.2, 35.6)		53.9	(52.0, 55.7)	
Walking ^g	39.7	(36.7, 42.7)		51.8	(49.3, 54.3)	
Type of claim						
Non-ACC ^h	36.7	(35.1, 38.2)	<0.001	53.1	(51.3, 54.7)	0.298
ACC ⁱ	29.8	(28.3, 31.4)		51.7	(49.3, 54.1)	
Region						
Earthquake ^j	37.4	(34.0, 41.0)	0.029	52.1	(49.5, 54.8)	0.693
Non-earthquake ^k	33.3	(32.1, 34.6)		52.8	(51.3, 54.3)	
Employment						
Full-time ^l	40.2	(37.8, 42.6)	<0.001	54.9	(52.7, 57.1)	<0.001
Part-time	33.7	(30.7, 36.6)		56.4	(53.6, 59.2)	
Not working ^m	30.9	(29.5, 32.3)		50.4	(48.5, 52.4)	

^a17 (7.5%) values missing; ^b5 (8.5%) values missing; ^c8 (7.1%) values missing; ^d9 (8.3%) values missing; ^e5 (6.9%) values missing; ^f7 (6.8%) values missing; ^g8 (4.7%) values missing; ^h3 (5.3%) values missing; ⁱ19 (8.3%) values missing; ^j3 (3.5%) values missing; ^k14 (9.3%) values missing.

Figures 7.6 and 7.7 depict scatterplot of participant's SF36v2 mental component scores and physical component scores over (i) age (years) and (ii) years since injury, together with a superimposed lowess curve (a non-parametric mean estimator function), respectively. No significant relationships between participants' SF36v2 mental component summary score over (i) age (years) ($P=0.99$) and (ii) years since injury (years) ($p=0.98$) was observed. Moreover, there was no significant relationship between participants' SF36v2 physical component summary score over (i) age (years) ($p=0.17$) and (ii) years since injury (years) ($p=0.68$).

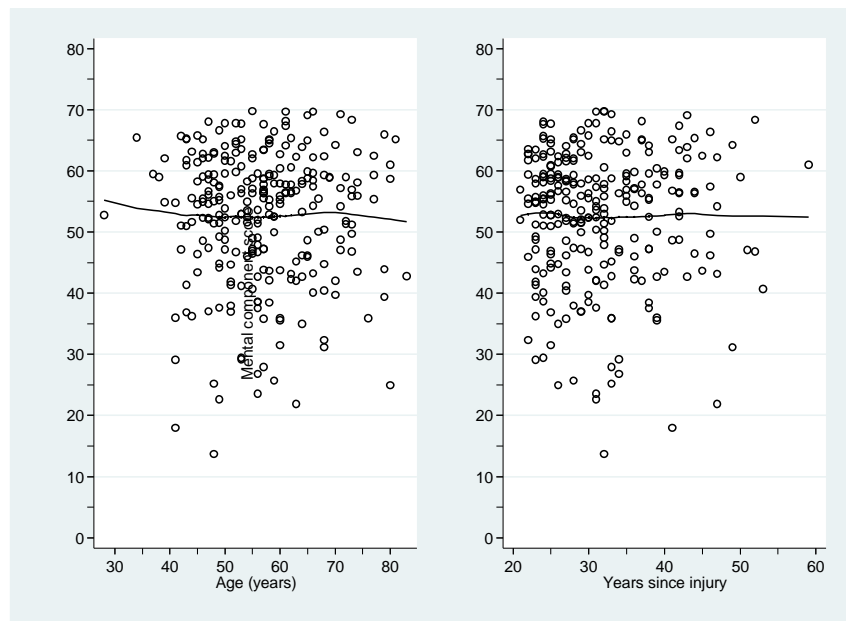


Figure 7.6 Scatterplot of participant's SF36v2 mental component score over (i) age (years) and (ii) years since injury, together with a superimposed lowess curve (a non-parametric mean estimator function)

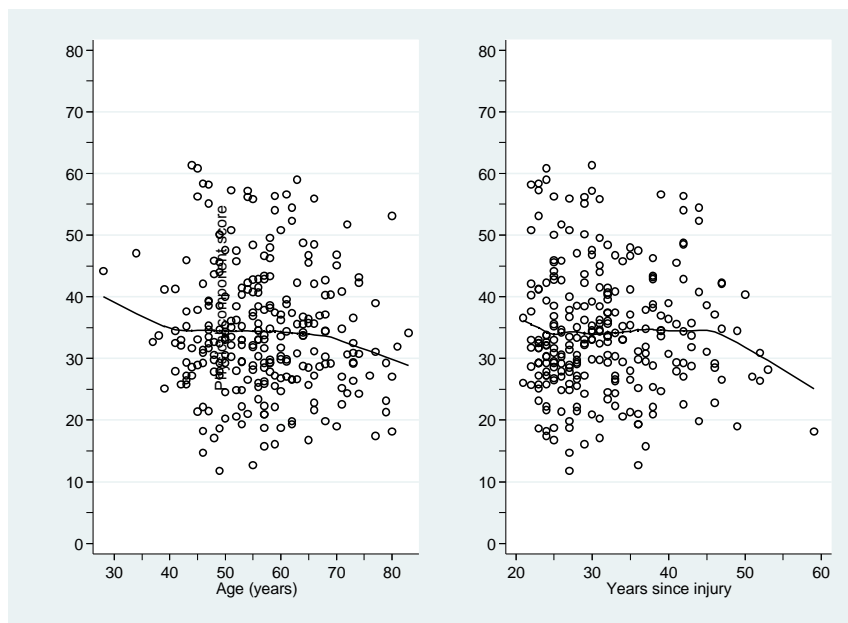


Figure 7.7 Scatterplot of participant's SF36v2 physical component score over (i) age (years) and (ii) years since injury, together with a superimposed lowess curve (a non-parametric mean estimator function)

Table 7.21 sets out health problems as reported by participants. The most frequently reported health problem was high blood pressure or hypertension reported by 85 (31.1%) participants, followed by 75 (27.4%) participants indicating they had arthritis or rheumatism, and 72 (26.3%) participants indicating they had a kidney or urinary tract conditions. Forty (14.6%) participants reported having diabetes, followed by 39 (14.3%) reporting respiratory conditions and then 37 (13.5%) reporting heart troubles. Regarding cancer, 22 (8.1%) participants indicated that they had skin cancer and 13 (4.8%) participants mentioned other forms of cancer.

The Health of New Zealand Adults survey 2011/12 reported one in six (16%) adults aged 15 years and over, took medication for high blood pressure and one in ten (10%) for high cholesterol. One in 20 adults (5.5%) had been diagnosed with ischemic heart disease and 2% had incurred a stroke. Both these conditions mainly affected adults aged 55 years and older. Other conditions reported included chronic pain (16%), arthritis (15%), asthma (11%) and diabetes (5.5%) (Ministry of Health, 2012).

The sample of people ageing with SCI had a much higher percentage of people reporting high blood pressure or hypertension compared to the Health of New Zealand Adults survey 2011/12. It is important to note the sample of people ageing with SCI was generally older than the sample of adults in the Health of New Zealand Adults survey 2011/12. Hitzig et al. (2008) found with SCI the odds of developing cardiac complications or high blood pressure increased per year with age. Also tetraplegics can have periodic high blood pressure problems relating to autonomic dysreflexia which can cause potentially life-threatening hypertension if not managed appropriately.

Table 7.21 Participants reporting that a doctor, nurse or other health care worker had told them they have one or more health problem

Health Problem	n	%
High blood pressure or hypertension ^a	85	(31.1)
Arthritis or rheumatism ^b	75	(27.4)
Chronic kidney or urinary tract conditions ^b	72	(26.3)
Hearing impairment ^c	51	(18.9)
Bowel disorders (e.g. colitis or polyps) ^a	41	(15.0)
Diabetes ^b	40	(14.6)
Other respiratory conditions (e.g. bronchitis) ^a	39	(14.3)
Heart trouble (e.g. angina or myocardial infarction) ^b	37	(13.5)
Asthma ^d	35	(12.9)
Chronic skin conditions (e.g. dermatitis or psoriasis) ^b	35	(12.8)
Sight impairment (that cannot be corrected by glasses) ^d	25	(9.2)
Skin cancer ^e	24	(8.9)
Hernia or rupture ^d	22	(8.1)
Stomach ulcer or duodenal ulcer ^a	17	(6.2)
Other forms of cancer ^a	13	(4.8)
Stroke ^e	10	(3.7)
Hepatitis ^e	8	(3.0)
Chronic liver trouble (e.g. cirrhosis) ^d	6	(2.2)
Epilepsy ^e	2	(0.7)

^a12(4.2%) values missing; ^b11(3.9%) values missing; ^c15(5.3%) values missing; ^d13 (4.6%) values missing; ^e14(4.9%) values missing;

Of the 275 participants who completed the first question of the AUDIT-C scale, 37 (13.5%) participants reported never consuming alcohol, 128 (46.5%) reported consuming alcohol monthly or two to four times a month. A total of 110 (40%) participants reported consuming alcohol weekly with 52 (18.9%) reporting that they drank alcohol two to three times a week and 58 (21.1%) reporting they drank alcohol four times or more a week. An addendum to the Health of New Zealand Adults 2011/12 survey on alcohol consumption indicated 80% of adults 15 years and older had consumed alcohol in the past 12 months (Ministry of Health, 2013). While the proportion of alcohol consumers in the study sample of 86.5% was higher than the Health of New Zealand Adults 2011/12 survey of 80% ($p=0.007$, exact binomial test of proportions), age dependence of alcohol consumption is likely to explain the difference.

Table 7.22 Reported alcohol consumption using the AUDIT Scale

Characteristic	n	(%)
<i>Frequency of alcohol consumption^a</i>		
Never	37	(13.5)
Monthly or less	76	(27.6)
2 to 4 times a month	52	(18.9)
2 to 3 times a week	52	(18.9)
4 or more times a week	58	(21.1)

^a9 (3.2%) values missing;

In Table 7.23, 243 (88.4%) participants reported they were not current smokers. Of the 32 (11.6%) who did report that they were current smokers, 17 (53.1%) reported smoking between one to ten cigarettes a day, 10 (31.2%) smoked between 11 to 20 cigarettes a day and 5 (15.6%) smoked 21 to 30 cigarettes a day. It is interesting that 125 (51.4%) participants indicated they had been previous smokers therefore indicating that many had given up smoking. The Health of New Zealand adults 2011/12 survey indicated that the daily smoking rate has dropped considerably over the past 15 years from 25% in 1996/97 to 17% in 2011/12 (Ministry of Health, 2012). The study sample of people with SCI had a non-smoking rate of 88.4%, which was higher than the Health of New Zealand Adults 2011/12 survey of 83% ($p=0.02$, exact binomial test).

Table 7.23 Reported smoking trends among participants

Characteristic	n	(%)
<i>Current Smoker^a</i>		
Yes	32	(11.6)
No	243	(88.4)
<i>Quantity of daily smoking consumption^b</i>		
1 to 10 a day	17	(53.1)
11 to 20 a day	10	(31.2)
21 to 30 a day	5	(15.6)
<i>Previous smoker^c</i>		
Yes	125	(51.4)
No	118	(48.6)

^a9(3.2%) values missing ^b252(88.7%) values missing; ^c41(14.4%) values missing.

Table 7.24 reported physical activity over the previous seven days and the previous six months. Of the 79 (30.0%) participants who indicated they undertook no exercise over the previous seven days 37 (46.8%) were tetraplegic (of whom 20 were women), 30 (38.0%)

paraplegic, and 12 (15.2%) walking. Also 25 (31.6%) participants who undertook no exercise were aged 65 years or older. Forty (15.2%) participants indicated they were physically active 15 minutes or longer between one to two days over the previous seven days and 96 (36.5%) indicated they were physically active 15 minutes or longer between three to six days. Of the 48 (18.3%) participants who indicated they were physically active 15 minutes or longer each of the previous seven days, 14 (29.2%) were tetraplegic, 19 (39.6%) paraplegic, and 15 (31.2%) walking.

When looking at physical activity over the previous six months, of the 57 (21.3%) participants that indicated they undertook no physical activity and did not intend to, 28 (49.1%) were tetraplegics, 17 (29.8%) paraplegic, and 12 (21.1%) walking. Also 22 (37.9%) of these inactive participants were aged 65 years and older. Eighty-seven (32.2%) participants indicated they undertook some physical activity but not regularly, whereas 111 (41.6%) participants indicated they undertook the regular physical activity of whom 11 (4.1%) had started within the last six months. Of the 111 participants who undertook physical activity regularly, 31(28.0%) were tetraplegic, 48(43.2%) paraplegic, and 32 (28.8%) were walking. In general terms the majority of participants reported doing some exercise, with a considerable number indicating they undertook regular physical exercise. It seems that those participants who indicated they did no exercise were more likely to be tetraplegic and/or aged 65 years and older. The Health of New Zealand Adults 2011/12 survey reported just over half (54%) of all adults are physically active. The Ministry of Health recommends that adults do at least 30 minutes of moderate to intense physical activity (such as brisk walking) at least five days a week. Older adults aged 75 years and over were less likely to meet the physical activity recommendations (Ministry of Health, 2012). The nature of the sample and elicitation means that statistical comparisons cannot be undertaken with validity.

Table 7.24 **Reported physical activity**

Activity	n	(%)
<i>Over the last 7 days were you active for 15 minutes or more^a</i>		
0 days	79	(30.0)
1 day	21	(8.0)
2 days	19	(7.2)
3 days	22	(8.4)
4 days	19	(7.2)
5 days	28	(10.6)
6 days	27	(10.3)
7 days	48	(18.3)
<i>Physical activity over the last 6months^b</i>		
Not regularly physically active and do not intend to be so	58	(21.6)
Not regularly physically active but am thinking about starting	13	(4.8)
Some physical activity but not regular physical activity	87	(32.3)
Regularly physically active but only began in last 6 months	11	(4.1)
Regularly physically active and have been so for longer than 6 months	100	(37.2)

^a 21 (7.4%) values missing; ^b 15 (5.3%) values missing.

Social interaction of participants

Table 7.25 describes the type of support and care participants provided to others. One hundred and thirty (48.3%) participants indicated they rarely or never contributed time and/or labour to volunteer activities. Of the 205 participants who did indicate they contributed time and/or labour to volunteer activities, 58 (21.6%) indicated they contributed their time often or very often, with 81 (30.1%) indicating they sometimes provided time and/or labour to volunteer activities. One hundred and forty four (53.7%) participants indicated they never provided unpaid care for grandchildren or other people's children. Of the 124 participants who did indicate they provided unpaid care for grandchildren or other people's children, 8 (3%) indicated it was provided on a daily basis, 25 (9.3%) on a weekly basis, and 91 (34%) occasionally. The New Zealand General Social Survey: 2010 results indicated that of the total New Zealand population aged 15 years, 32.4% undertook voluntary work and 65.4% undertook unpaid work (Statistics New Zealand, 2011). Although difficult to make direct comparison, in general terms it would seem to indicate that people ageing with SCI were contributing to volunteer activities to a similar extent as the general population.

Nineteen (7.3%) participants indicated they provided care or assistance to someone who lived with them due to a long-term illness, disability or frailty with 33 (12.7%) indicating they provided assistance to someone who did not live with them. In the majority of instances care

was provided to one person. Of the 50 participants who provided information about the frequency of assistance or care provided, 9 (18.0%) indicated that it was on a daily basis and another 10 (20%) indicated it was several times a week. Five (10.0%) participants indicated that it was once a week with 10 (20%) indicating that it was every few weeks and 16 (32%) indicating it was less often. Of the 48 participants who indicated how much time they spent providing care and assistance on each occasion, 8 (17.8%) indicated it was day and night, 25 (55.6%) participants indicated it was several hours on each occasion and 12 (26.7%) indicated that it was approximately one hour on each occasion.

Table 7.25 Reported provision of support and care for others

Activity	n	(%)
<i>Contribution of time and/or labour to volunteer activities ^a</i>		
Very often	19	(7.1)
Often	39	(14.5)
Sometimes	81	(30.1)
Rarely	66	(24.5)
Never	64	(23.8)
<i>Providing unpaid care for grandchildren or other people's children ^b</i>		
Yes, daily	8	(3.0)
Yes, weekly	25	(9.3)
Yes, occasionally	91	(34.0)
No, never	144	(53.7)
<i>Number of people with long-term illness, disability or frailty care is regularly provided for ^c</i>		
1 person	23	(26.4)
2 people	8	(9.2)
more than 2 people	3	(3.4)
N/A	53	(60.9)

^a15 (5.3%) values missing; ^b16 (5.6%) values missing; ^c 197 (69.4%) values missing

Table 7.26 summarises living distances and communication between participants and their family/whānau, children and siblings, as well as friends. The large majority had relatives living within close proximity to them, with 69.4% living within a distance of 15 km. Forty two (16.2%) participants indicated their family/whānau (excluding spouse, children and siblings) lived in the same house or within 1 km of them. This was followed by 54 (20.8%) living within 5 km and 84 (32.4%) living between 6 to 15 km, followed by 70 (27%) living 50 km or more away.

Forty-nine people (21%) had a child either living in the same house or living within 1 km from them. This was followed by 27 (11.6%) living within 5 km, 38 (16.3%) living between

16 to 50 km away, and 66 (28.3%) living 50 km or more away. Fifty-three (22.7%) participants reported not having children. In regards to siblings, 122 (48.4%) participants reported their nearest sibling being 50 km or more from them.

A majority of participants were in contact or undertook activities regularly with family/whānau, and friends. Of those who responded, 236 (87.1%) reported having regular contact with their family/whānau and 232 (85.6%) were in regular contact with their friends. In regard to participating in activities 187 (70%) participants reported participating regularly in family/whānau activities, with 136 (50.9%) indicating they had family/whānau or friends over for a meal at least once a month. The New Zealand General Social Survey: 2010 results indicated that of the total New Zealand population aged 15 years and older, 83.9% had face-to-face contact with family members living in another household, and 94.8% having non face-to-face contact with the family members over the past four weeks (Statistics New Zealand, 2011). The difference in the nature of these questions means that valid statistical comparison cannot be drawn.

In regards to interaction with other people, 97 (36.6%) participants reported that they interacted with relatives on a daily basis, with 107 (40.3%) interacting two to three times a week or at least weekly. Fifty one (18.8 %) participants interacted with friends and the community daily with the majority of 163 (60.2%) reporting that they interacted two to three times a week or at least weekly. Twenty seven (10.2%) participants reported interacting with neighbours daily, with 125 (47.4%) interacting with neighbours two to three times a week or at least once weekly.

Table 7.26 **Reported communication with family and whānau**

Characteristic	Family/whānau ^a (excluding spouse/child/sibling)		Child ^b		Sibling ^c	
	n	(%)	n	(%)	n	(%)
<i>Distance nearest relative/whānau, child, sibling live</i>						
Same house/within 1km	42	(16.2)	49	(21.0)	9	(3.6)
1-5km	54	(20.8)	27	(11.6)	41	(16.3)
6-15km	48	(18.5)	21	(9.0)	43	(17.1)
16-50km	36	(13.9)	17	(7.3)	25	(9.9)
50+km	70	(27.0)	66	(28.3)	122	(48.4)
NA/None living	9	(3.5)	53	(22.7)	12	(4.8)
<i>Contact with family/friends/whānau</i>						
	Yes n (%)				No n (%)	
Do you feel you have regular contact with your family/whānau? ^d	236 (87.1)				35 (12.9)	
Do you feel you have regular contact with your friends? ^d	232 (85.6)				39 (14.4)	
Do you regularly participate in family/whānau activities? ^e	187 (70.0)				85 (30.0)	
Do you have family/ whānau or friends over for a meal at least once a month? ^f	136 (50.9)				131 (49.1)	
<i>Interaction with other people</i>						
	Relatives ^g n (%)		Friends/ Community ^d n (%)		Neighbours ^h n (%)	
Daily	97 (36.6)		51 (18.8)		27 (10.2)	
2-3 times a week	42 (15.8)		75 (27.7)		44 (16.7)	
At least weekly	65 (24.5)		88 (32.5)		81 (30.7)	
At least monthly	26 (9.8)		23 (8.5)		49 (18.6)	
Less often	19 (7.2)		22 (8.1)		46 (17.4)	
Never/ I have none	16 (6.0)		12 (4.4)		17 (6.4)	

^a 25 (9.9%) values missing; ^b 51 (18%) values missing; ^c 32 (11.3%) values missing; ^d 13 (4.6%) values missing; ^e 12 (4.2%) values missing; ^f 17 (6%) values missing; ^g 19 (6.7%) values missing; ^h 20 (7%) values missing.

Table 7.27 summarises the interaction and communication that participants had with other people. In regards to trusting people, of those who responded, 184 (67.9%) reported that people could always or usually be trusted. Among participants who responded in regard to feeling lonely or isolated over the previous 12 months, 81 (29.6%) indicated feeling lonely sometimes or most of the time, with a further 5 (1.8%) indicating that they always felt lonely. A majority (188, 68.6%) reported that they had rarely or never felt lonely or isolated. The 2006 HWR sample indicated that 77.2% of people could be always or usually trusted, a

proportion significantly higher than the study sample ($p=0.004$, test of two sample proportions). In regards to loneliness, 21.7% indicated that they felt lonely sometimes or most of the time (Stephens & Noone, 2008). While the number of people in the sample of ageing SCI who indicated they felt lonely sometimes or most of the time (29.6%) was significantly ($p=0.002$, test of two sample proportions) higher than that reported by the 2006 HWR sample (21.7%), it is important to remember that the majority of ageing SCI did not feel lonely or isolated.

A relatively small number of participants, 56 (21%), indicated they had attended religious meetings regularly or occasionally, with 210 (79%) reporting they had not. In regards to attending social groups, clubs etc., 132 (51.4%) participants indicated they attended regularly or occasionally. Participants used technology actively with 225 (93.1%) using the telephone, 191 (71.3%) regularly used e-mail to contact family/whānau, and 147 (55.3%) regularly used the internet. This usage is relatively similar to the HWR sample and the 2006 Census. Among the HWR sample 96.4% reported having access to telephone and 58% having access to the internet. Technically the study sample had a significantly lower proportion of telephone usage ($p=0.008$, two sample proportion test) than the HWR sample, but a similar usage of internet ($p=0.38$). The 2006 Census reported 91.6% of people had access to a telephone and 60.5% access to the internet (Stephens and Noone, 2008).

Table 7.27 Interacting and communicating with other people

Characteristic	n	(%)
<i>Trusting people^a</i>		
People can always be trusted	3	(1.1)
People can usually be trusted	181	(66.8)
Usually can't be too careful	73	(26.9)
You almost always can't be too careful	9	(3.3)
Don't know	5	(1.8)
<i>In the last 12 months feeling lonely or isolated^b</i>		
Always	5	(1.8)
Most of the time	9	(3.3)
Sometimes	72	(26.3)
Rarely	90	(32.8)
Never	98	(35.8)
<i>Attendance to religious meetings^c</i>		
Yes, regularly	24	(9.0)
On occasion	32	(12.0)
No	210	(79.0)
<i>Attendance social groups, clubs, etc^d</i>		
Yes, regularly	55	(21.4)
On occasion	77	(30.0)
No	125	(48.6)
	Yes	No
<i>Use of technology to contact people</i>		
	n (%)	n (%)
Use of a telephone to contact people ^b	225 (93.1)	19 (6.9)
Regular use of email to contact family/whānau ^e	191 (71.3)	77 (28.7)
Regular use of the internet (chat rooms etc) ^c	147 (55.3)	119 (44.7)

^a13(4.6%) values missing; ^b10(3.5%) values missing; ^c18(6.3%) values missing; ^d27(9.5%) values missing; ^e16(5.6%) values missing.

The Social Provision Scale (SPS) subscales in Table 7.28 summarise 24 statements (ranked using a four item Likert scale) covering attachment, social integration, reassurance of worth, reliable alliance, guidance, and opportunity for nurturance and related to perceptions of support. There were significant mean differences (all $p < 0.001$) between the SCI and HWR populations (Stephens & Noone, 2008) on all subscales except reliable alliance ($p = 0.31$). Interestingly, the individual subscale SDs for people ageing with SCI were significantly smaller than the HWR population (all $p < 0.001$), therefore SCI scores were generally higher and less variant than their HWR counterparts and less likely to be more 'extreme'. In general

terms, the HWR population had a higher level of perceived social support than the SCI population.

Table 7.28 Descriptive statistics of SCI and HWR populations on each subscale of the social provisions measure of perceived social support, together with a comparison of their mean differences

SPS Subscales	SCI			HWR ^e			Mean	
	n	Mean	(SD)	n	Mean	(SD)	Difference	(95% CI)*
Reliable alliance	270 ^a	13.73	1.40	6462	13.82	1.96	-0.09	(-0.26, 0.08)
Attachment	270 ^a	12.59	1.68	6400	13.06	2.26	-0.47	(-0.68, -0.26)
Guidance	271 ^b	13.01	1.53	6476	13.39	2.17	-0.38	(-0.57, -0.19)
Opportunity for nurturance	269 ^c	11.68	1.73	6471	12.47	2.21	-0.79	(-1.00, -0.57)
Social integration	267 ^d	12.65	1.48	6431	13.02	1.99	-0.37	(-0.55, -0.18)
Reassurance of worth	267 ^d	12.57	1.50	6394	12.93	1.93	-0.36	(-0.55, -0.17)

*Note:**calculated using Student's t-test with Satterthwaite's approximation used due to unequal group variances. ^a 14(4.9%) values missing; ^b 13(4.6%) values missing; ^c 15(5.3%) values missing; ^d 17(6.0%) values missing; ^e Source Stephen & Noone (2008)

Health service use

Table 7.29 describes reported community health service use over the previous 12 months. The reported highest health service use was 156 (54.9%) participants using General Practice nurses, followed by 154 (54.2%) using a pharmacist for health advice or obtaining medications. District, public health or other nurses were reported to have been used by 107 (37.7%) participants. The Health of New Zealand Adults 2011/12 survey reported one third of adults had visited a GP practice nurse in the past year which was similar to rates reported in 2006/07 (Ministry of Health, 2012).

Table 7.29 Reported community health service use over the previous 12 months

Type of health service used	n	%
General Practice nurse without doctor	156	(54.9)
Chemist or pharmacist, for health advice or medication only	154	(54.2)
Dentist or dental nurse	121	(42.6)
District, public health or other nurse	107	(37.7)
Other specialist medical practitioner	91	(32.0)
Optician or optometrist	68	(23.9)
Physiotherapist	61	(21.5)
Podiatrist or chiropodist	43	(15.1)
Occupational or speech therapist	40	(14.1)
Alternative therapist such as a naturopath, homoeopath, iridologist or acupuncturist	21	(7.4)
Psychologist or counsellor	17	(6.0)
Chiropractor or osteopath	13	(4.6)
Traditional healer such as a tohunga, rongoa, Maori specialist or fofo	2	(0.7)
Maori health worker, Pacific Island health worker	3	(1.1)

Table 7.30 describes reported GP usage over the previous 12 months. A clear majority of 246 (90.8%) participants had visited their GP, with 111 (47.6%) indicating they had visited their GP between three to five times. A further 58 (24.9%) had visited their GP six times or more. The Health of New Zealand Adults survey 2011/12 reported most people (78%) had visited a GP in the past year however this was lower than the 2006/07 survey with 81% attendance being reported. This would tend to indicate that people ageing with SCI are significantly more likely to visit their GPs at least once in the previous 12 months compared to their counterparts participating in the Health of New Zealand Adults survey ($p < 0.001$, exact binomial test).

Table 7.30 Reported General Practitioner usage over the previous 12 months

Activity	n	(%)
Visit a GP^a		
Yes	246	(90.8)
No	25	(9.2)
Frequency of GP visits^b		
1	19	(8.2)
2	45	(19.3)
3 to 5 times	111	(47.6)
6 to 11 times	37	(15.9)
12 times or more	21	(9.0)

^a 13 (4.6%) values missing; ^b 51 (17.9%) values missing.

Table 7.31 describes the reported hospital admissions over the previous 12 months. A majority of 142 (52.8%) had used or been admitted to a hospital in the previous 12 months. Of the 180 participants who reported whether they had been admitted overnight or longer, 100 (55.6%) indicated they had not been admitted, 70 (38.9%) had been admitted once or twice, with 10 (5.5%) indicating they had been admitted three times or more. The majority of 198 participants (72.5%) had not attended a hospital emergency department over the previous 12 months; with 64 (23.4%) indicating they had visited the emergency department once or twice, and 11 (4.1%) indicating that it had been three times or more. The Health of New Zealand Adults survey 2011/12 reported one in eight adults (13%) had visited an after-hours medical centre in the past year. This would indicate that the sample population compared to the New Zealand population had a significantly higher attendance rate ($p < 0.001$, exact binomial test) of needing to receive emergency medical treatment at least once in the previous 12 months.

Table 7.31 Reported hospital admissions over the previous 12 months

Activity	n	%
<i>Hospital service/admissions in the last 12 months^a</i>		
Yes	142	(52.8)
No	127	(47.2)
<i>Hospital admissions for one night or longer in the last 12 months^b</i>		
Never admitted overnight	100	(55.6)
1 to 2 times	70	(38.9)
3 to 4 times	8	(4.4)
5 or more times	2	(1.1)
<i>Hospital Emergency Department visits in the last 12 months^c</i>		
Never	198	(72.5)
1 to 2 times	64	(23.4)
3 to 4 times	10	(3.7)
Five or more times	1	(0.4)

^a15 (5.3%) values missing; ^b104 (36.6%) values missing; ^c11 (3.9%) values missing.

7.4 Conclusions

Key findings

Generally, people living with long-term SCI had socio-demographic, QOL, social support networks and community involvement profiles that were largely consistent with similar aged groups of able-bodied people. Surprisingly, and counter to that anticipated from Phase 1, the quantitative results indicate that time since injury regardless of age at the time of injury and

whether participants received support from Ministry of Health and ACC were not significantly related to rated standard of living, satisfaction with standard of living and income meeting everyday needs. However, what was significant was injury level; with tetraplegics almost 4 times and paraplegics twice as likely to rate standard of living high or fairly high compared to SCI people who indicated they were walking. Those who were in a relationship were twice as likely to rate standard of living high or fairly high compared to those not in a relationship. These findings support previous literature on ageing with SCI and QOL (McColl et al., 2004; Sakakibara et al., 2012), as well as add support to the concept of the ‘disability paradox’ originally proposed by Abrecht and Devlieger (1999).

People in a relationship were almost twice as likely to consider their income was more than enough or enough to meet their needs compared to those people not in a relationship. Females were 50% less likely to consider their income more than enough or enough to meet their needs compared to males. Similar findings have been found in literature on ageing with SCI (Liem et al., 2004; McColl et al., 2004; Sakakibara et al., 2012).

Being able to establish significant differences in the circumstances of health and employment between participants who receive support from Ministry of Health and ACC, was complex, with a number of people indicating that they received funding for care and support from more than one source. There were instances where both Ministry of Health and ACC were indicated as funding sources. In regards to employment the majority of participants did not respond, either because they chose not to or they did not have an occupation.

Demographic profile

In general terms, marital status, income and living status profiles were similar to the HWR sample and the 2006 Census data (Statistics New Zealand, 2007a; Stephens & Noone, 2008). The study population had a higher percentage of people with post school education compared with the HWR sample and the 2006 Census data. The study population had a higher percentage of Europeans and fewer Māori compared to the 2006 Census data. A majority of the study population did not respond regarding occupation; however, of those who did respond, the largest group of people was classified as professional followed by managers which is similar to the 2006 Census data. The study population had few people working as machinery operators, drivers or labourers compared to the HWR sample and the 2006 Census data. Income came from various sources such as part-time or full-time employment, ACC,

invalid's benefit, unemployment benefit, interest, shares, rent, superannuation etc. The percentage of participants earning an annual income of \$40,000 or less was similar to that of the general population and the HWR sample. Approximately a third of participants were in some form of superannuation scheme. A considerable number of participants who were receiving ACC or the invalid's benefit indicated they would prefer to be working part-time or full-time, which would suggest many participants' employment and income desires were not being met.

Injury characteristics

The study population had a ratio 4M:1F ratio with a mean age of 57.2 years, a mean age when injured of 25.7 years, and a mean time since injury of 31.6 years. Howard-Brown and Esplin (2013) found the New Zealand information in the Australian Rehabilitation Outcomes Centre register from 2010-12 had an average age of people with SCI of 49 years, with 70% being male and 17% being Māori. ACC database information indicates its 100 SCI per annum were 75% male with an average age at time of injury of 34 years. Wyndaele and Wyndaele (2006) found a worldwide SCI ratio of 3.8M:1F, with a mean age when injured of 33 years. The split between injury and non-injury cause is reported as 55:45 percent by the spinal rehabilitation units (Howard-Brown & Esplin, 2013). In the study sample only 4% indicated that their SCI was caused by a medical condition. A possible explanation for this major difference is that the study sample consists of people with SCI sustained before 1 January 1990 and admitted to one of the two spinal units at a time when admission was for the treatment and rehabilitation of traumatic SCI. In recent years the admission criteria for the spinal units has changed and they now accept a wide range of non-traumatic SCI conditions as well as traumatic SCI.

The complex issue of people having neurologically complete or incomplete SCI with feeling or movement below the level of injury was highlighted with a number of people often using a combination of mobility aids such as manual and electric wheelchairs, crutches, and walking sticks. MVA and motorbike accidents combined to make up 50% of reported cause of injury among the study population followed by accidents caused by sport and falls. International research indicates that the most common cause of SCI is MVA, followed by falls predominantly in the over 60 years age group (Burt, 2004; Ho et al., 2007; Jackson et al., 2004; van den Berg et al., 2010). Dixon et al. (1993) found after reviewing the Health Statistics Services morbidity data that the leading cause of SCI in New Zealand in 1988 was MVA (54%) followed by falls (24%).

Care and support

The majority of the study population was receiving financial support for care and equipment from ACC, followed by support from the Ministry of Health or Ministry of Social Development. Funding is not straightforward, with joint ACC and Ministry of Health and/or Ministry of Social Development funding support also occurring. For example, a person can have their care and support funded by Ministry of Health then subsequently have an accident which enables them to qualify for funding support from ACC, or if someone is not working when they sustain their SCI they will receive the unemployment benefit or invalid's benefit and have their care and equipment paid by ACC. Care and/or home help support was organised the majority of the time by people in the household such as the SCI person, a spouse/partner, or a family member, rather than it being organised by an outside organization such as a nursing agency.

Quality of life and health

When the SF-36v2 multi-purpose health survey mean scores for the study population were compared to the 2006 HWR mean scores of the 55 to 69 years European age group (Stephens et al., 2010) they were all lower, except for the MCS mean scores, which were significantly higher. In general terms the higher the score the better people rate their health, lower the score worse they rate their health. Within the study population, people not in a relationship and not working showed significantly the lowest MCS mean scores. There was no significant relationship between the MCS score compared to age and time since injury. Tetraplegics who were on ACC and not working had the lowest PCS mean scores. There was no significant relationship between the participants' PCS scores and age or time since injury. Those people who lived in areas affected by the Canterbury earthquakes showed no significant differences in their rating of standard of living, satisfaction of standard of living and whether their income met their current needs when compared to other people in the study population.

The five most common health problems reported by the study population in order of frequency were high blood pressure or hypertension, arthritis or rheumatism, kidney or urinary tract conditions, hearing impairment, and bowel disorders. The Health of New Zealand Adults survey 2011/12 reported one in six people took medication for high blood pressure and one in ten for high cholesterol. One in 20 adults had been diagnosed with ischemic heart disease and 2% had incurred a stroke (Ministry of Health, 2012). The large

majority of the study population were not current smokers, with a considerable number indicating they had given up smoking. Nationally 17% of people currently smoke (Ministry of health, 2012) compared to 11.6% of study participants. In general terms the majority of participants reported doing some exercise with a considerable number indicating they undertook regular exercise. Tetraplegics and/or those aged 65 years and older were more likely to indicate they were not exercising. Ginis et al. (2011) suggest that the loss of fitness and independence associated with physical inactivity can significantly influence the development of secondary conditions, overall QOL and community participation. They believe it is important that physical activity is promoted to improve the health and fitness and overall QOL of people with SCI, and have developed the first evidence-based physical activity guidelines for people with SCI.

Social and community interaction

Comparison of the Social Provision Scale (SPS) subscales between the study population and the HWR sample population, in general terms, indicated the HWR population had a higher level of perceived social support than the SCI population in five of the six subscales. The majority of the study population reported undertaking activities regularly with family/whānau and friends such as having regular contact with them or having people over for a meal or vice versa. The telephone or the internet was regularly used to keep in contact with others. The majority had family/whānau either living with them or within 15 km of where they lived. Both the majority of the study population and the 2006 HWR study participants indicated that people can always or usually be trusted. The majority of participants indicated that they rarely or never felt lonely or isolated, however approximately one third of study participants did indicate feeling lonely sometimes, most, or all of the time. The 2006 HWR sample reported 21.7% of people experiencing loneliness.

Concluding comment

Those people interviewed in Phase 1 recognised that as they had aged their health issues had become more complicated and, in recent years, they had started to develop a variety of secondary conditions which in some cases had severely affected their health and QOL. Also the impact of the different funding criteria and policies between ACC and Ministry of Health and/or Ministry of Social Development was relatively clearly defined by those people interviewed. However, Phase 3 quantitative analysis failed to demonstrate that time since

injury to be a significant factor in rated standard of living, satisfaction with standard of living, and income meeting current needs. The time living with SCI did not appear to be as clearly identified as a reason for the development of secondary conditions compared to those people interviewed in Phase 1. It was also found in Phase 3 that the distinction between those people receiving funding from ACC and non-ACC sources was less clear with many people receiving funding from more than one source.

Chapter 8: Discussion

8.1 Introduction

The aim of this thesis has been to redress an information deficit and to develop a better understanding of the health, living circumstances and QOL of people ageing with SCI in New Zealand. To contextualise the research into ageing with SCI, Chapter 1 presented an outline of international and New Zealand demographic trends, and of theories in ageing and disability. This included looking at theories primarily associated with ageing and with disability, in turn, then exploring the development of common themes to gain an understanding of the relatively new phenomenon of ageing with a major long-term disability. Chapter 2 discussed the development of political activism of disabled people and older people internationally and in New Zealand. Also discussed is the development of key New Zealand government policies and strategies that have affected not only people ageing with SCI but all New Zealanders, with or without disability. In Chapter 3 a focused literature review of international research on ageing with SCI was presented exploring issues such as ageing and time since injury, the development of secondary conditions, QOL and the impact of environmental factors.

The research study used a mixed methods sequential research approach which was outlined in Chapter 4. The qualitative research in Phase 1 assisted with the development of the quantitative research enquiry in Phase 3. Chapters 5, 6 and 7 report the findings from the mixed method research project involving three phases. Phase 1 consisted of interviewing 12 people who had lived with SCI for a minimum of 25 years. With the assistance of the ASRU and BSU, Phase 2 established a database of ageing people with SCI with reliable contact details which enabled potential respondents to be invited to participate in Phase 3. The final phase entailed a cross-sectional national survey of people who had sustained SCI prior to 1 January 1990, and Chapter 7 reports the results from the questionnaires completed by these 284 people.

The next section of this chapter will reflect on the research. In sections 8.3 to 8.6 the key issues identified in this New Zealand research will be discussed in the context of the current understanding of those issues in relation to ageing with SCI. The limitations of the research

methods are reviewed and commented on in section 8.7 and recommendations made in section 8.8. Finally, concluding comments will be made.

8.2 Reflections on the research

The key findings of each phase have been reported fully in Chapters 5 to 7. This section will concentrate on reflecting on some of the unique insights gained from undertaking the research.

In Phase 1 it was clear that the interviews with the 12 people who had lived with SCI 25 years and longer supported many of the conclusions from international research relating to ageing with SCI (Adkins, 2004; Charlifue et al., 1998; Charlifue et al., 2004; Charlifue et al., 1999; Coll, 2007; Frankel et al., 1998; Hitzig et al., 2008; Kemp et al., 2004; Krause & Broderick, 2005; Krause & Sternberg, 1997; McColl et al., 2003; Weitzenkamp et al., 2001; Whiteneck et al., 1993; Whiteneck et al., 2007; Wyndaele & Wyndaele, 2006). The interviews gave people a chance to share their individual unique stories which provided wonderful insights into the major issues facing people who had lived with SCI for a prolonged period. Some people were surprised they were still alive and had not planned for getting older. In one instance, the person had lived with SCI for over 50 years and was dealing with major physical problems and financial constraints that he had not expected to encounter as he never expected to live so long. It was a privilege to be able to interview a group of people who often had overcome major obstacles and come to terms with living with SCI, some of them in the 1960s when there was little general public understanding of SCI and no financial governmental support for disabled people. The first specialised four bed spinal unit opened at Christchurch Hospital in 1965 and the Government did not start contributing to the purchase of wheelchairs until 1972. Participants emphasised their personal devastation following the initial injury and coming to terms physically and emotionally with living with SCI, especially learning to deal with bowel and urinary incontinence.

Many people had gone on to live full and active lives; working, getting married, having children and often making major contributions to society. Some of those interviewed had been actively involved in pursuing the rights of disabled people in New Zealand in the early 1970s. It was recognised that the community was now much more accepting of disabled people, possibly assisted by appropriate government legislation. The majority of those interviewed had an attitude of ‘just getting on with their lives’. However, there was acceptance that they

and their partners were getting older and becoming more physically compromised, with some of those people developing specific secondary complications which were starting to affect their QOL. Frustration was expressed regarding the funding differences between people who received assistance from ACC compared to the Ministry of Health and/or Ministry of Social Development. The knowledge gained from undertaking the interviews was shared in presentations at local disability research forums, conferences (Smaill, 2007) and an international conference (Smaill, 2008) with there being considerable positive feedback on the value of the research being undertaken.

Phase 2 of the research, required the creation of a database of people ageing with SCI which was essential to be able to conduct Phase 3 the national survey. This was the first time that such a comprehensive national database of people ageing with SCI had been compiled and many more people were found than anticipated. The actual number of people ageing with SCI in New Zealand was relatively unknown to spinal specialists, DHBs, ACC, researchers and the Ministry of Health. Until this 'hidden population' was identified with basic demographic details it was not possible to design the cross-sectional survey for the doctoral study. It was fortunate that there was considerable support from the NZST and the two spinal units to provide assistance to research the various PIMS that existed.

With the literature indicating that secondary conditions start to develop around 20 years post injury (Adkins, 2004; Capoor & Stein, 2005; Kemp et al., 2004; McColl et al., 2003), the decision was made to concentrate on identifying people with SCI who sustained an injury prior to 1 January 1990. Most of the sources reviewed were no longer in use, were ad hoc, or were incomplete in the way they had recorded information. For example, there was a handwritten 'Deaths book' that was used in the 1970s by the ASRU to record known people with SCI who had died. This was used as one source to assist with eliminating names of people who were deceased. It was initially considered that when using these resources it might be possible to identify the number of people who had died since the onset of their SCI and the reasons for this death. However, this information had not been systematically recorded and simply was not available in any reliable form. Considerable effort went into collecting as many potential participants as possible. It was necessary to eliminate those individuals who were deceased or residing overseas. It was decided that the most accurate way to achieve this and check individual contact details was by referring to the Ministry of Health's PIMS although there are limitations associated with using the system. If someone had not been in

hospital for many years and had moved from the address last logged in the PIMS it was unlikely that person would be able to be contacted.

The need to put the database together and the technical issues associated with achieving this, reinforced the necessity for New Zealand to have a well organised and managed national SCI register that could provide up-to-date contact details on people with SCI. The concept of such a register is discussed further on in section 8.5. With more people ageing with SCI being found than anticipated, it was a positive result for the research study and meant that the number of people available to be contacted increased the likelihood of a substantial number of respondents. However, it does raise questions as to why these people were not readily identified and part of a PIMS whereby people ageing with SCI were monitored and periodically medically reassessed. It also raises the issue as to whether this growing population of ageing SCI people and their needs are being under estimated and under resourced within the health system.

The aim of Phase 3 was to survey a national cohort of ageing SCI people to address the important issues identified in the literature and Phase 1 of the research, and to provide a basis for a selective comparative analysis with non-disabled people. This included establishing socio-demographic and injury profile of people ageing with SCI in New Zealand. Also it involved establishing if there were differences in employment, living status, health and well-being, physical activity, and social support profiles of people ageing with SCI in New Zealand. The survey results indicated that tetraplegics rated their standard of living four times higher than SCI people who indicated they were walking. On the face of it, such a result appears counter-intuitive, however it has been reported in other studies on ageing with SCI (Charlifue & Gerhart, 2004). These findings add support to the concept of the 'disability paradox' (Albrecht & Devlieger, 1999) which suggests the more severely disabled develop an understanding of their condition or disability and take control, introducing order and predictability in their lives. This is discussed in more detail in section 8.4.

The aim to collect socio-demographic details of a sample of people ageing with SCI was achieved. Also some comparison was able to be made with able-bodied people of a similar age group. For example, it was found that marital status, income, living status and having good social support networks and community involvement were similar to the HWR sample and the 2006 Census data (Statistics New Zealand, 2007a; Stephens & Noone, 2008).

Previous international research suggested that time since injury would be an important factor in relation to rated standard of living, satisfaction with standard of living, and income meeting current needs. However, this was not the case in the present study. The explanation for this is not obvious. The sample group were successful long term ‘survivors’ of SCI who may have different personality profiles to those who did not survive and had died. They have survived the initial trauma, rehabilitation and reintegration back into society learning to live with SCI. Possibly people with a positive attitude and outlook are more likely to cope with living and ageing with long-term SCI; so may represent those people who have been relatively successful at ageing with SCI. These may have been the type of people who consented and participated in the survey. Such people who have a more positive outlook on life may have not made an association with the possible social and/or medical complications they may be experiencing when subjectively rating their standard of living, satisfaction of standard of living and whether income met their current needs. Also it is possible participants did not recognise or appreciate that the length of time living with SCI increased the likelihood of developing the secondary (health) complications they possibly were experiencing. Alternatively, the care and support funded by the Ministry of Health and ACC in the community and the provision of medical services is of an appropriate standard that the length of time living with SCI and the associated secondary conditions that potentially develop have not had a significant impact on individuals ageing with SCI in New Zealand. Even though there is considerable literature indicating secondary conditions tend start to develop around the 20 to 25 years post injury (Adkins, 2004; Capoor & Stein, 2005; Kemp et al., 2004; McColl et al., 2003), it is possible that because of the high standard of care and support being provided that the sample group (with an average time since injury of 31.6 years) had yet to experience the development of major secondary conditions to any extent that compromised their daily lifestyle. This is expanded on in the next section 8.3.

In Phase 3, there was a delay in the sending out of the questionnaire due to the February 2011 earthquake and the frequent after-shocks that occurred in Christchurch and surrounding areas. The Department of Public Health and General Practice at the University of Otago Christchurch was badly affected, with minimal office support not always being available and staff and research students, including the researcher, being required to work from home for much of the 2011-2012 period. It was recognised that there were a considerable number of potential respondents living in Christchurch and surrounding areas and the decision was made

to wait until the aftershocks had ceased and major daily disruption had lessened before sending out the questionnaire, eventually in October and November 2011. It was thought that responses from those living in Christchurch and the surrounding areas may have possibly been different from those of respondents from the rest of the country; however, no significant differences were found. This could suggest that to delay the sending out of the questionnaires for a few months was appropriate.

8.3 Issues relating to ACC and the Ministry of Health and/or Ministry of Social Development

On the 1 April 1974 ACC was established to administer the *Accident Compensation Act 1972* which gave people injured through an accident a no fault entitlement to receive assistance on an individual basis. Over the years there have been various amendments; however, the basic intent remains the same. The Act was not made retrospective to include people seriously injured prior to 1 April 1974. This aspect has always been regarded as unjust by disabled people and also commented on by policy makers and the wider community (Barnett & Penny, 2004). The introduction of ACC highlighted inadequacies in both services and income support for people injured prior to 1 April 1974 and people with disabilities due not to injury but to illness or congenital disorder. The *Disabled Persons Community Welfare Act 1975* (DPCWA) improved both income benefits and community support services and structured disability welfare for the next 20 years (Barnett & Penny, 2004; Beatson, 2004; Office for Disability Issues Ministry of Social Development, 2013). Although there have been various amendments to both Acts over the years, New Zealand fundamentally still retains two disability support systems.

Those people interviewed in Phase 1 who had lived with SCI 25 years or longer and were under ACC discussed having mixed relationships with ACC, ranging from “*terrible*” to “*positive*”. Relationships often varied over the years when there were major changes in government or internal ACC policy changes as well as personnel changes, especially individual case managers. A common issue was the lack of information from ACC about entitlements and rights. Those respondents who were non-ACC considered it extremely unjust that ACC did not retrospectively accept people with SCI before 1 April 1974. Most of them felt considerably disadvantaged compared to those people who were under ACC. Some of the respondents interviewed had been politically active in disability groups that pursued the rights

of disabled people. Non-ACC respondents highlighted the fact that those people under ACC could receive ERC, which is 80% of a person's pre-injury taxable income, with no income means testing. In contrast, people not covered by ACC, regardless of the level of SCI, if not working, received the income means-tested invalid's benefit (unless 65 years or older at which time they received the New Zealand Superannuation) (Barnett & Penny, 2004; Paul et al., 2013). Non-ACC respondents had their care and equipment paid for by the Ministry of Health and social support by the Ministry of Social Development (which replaced the Ministry of Social Welfare). Some non-ACC respondents had lived with their SCI for so long that they incurred their injury before there was any type of government assistance available which required them to be innovative and determined to overcome major obstacles, often relying on family and community support.

Phase 3 sought to quantify the disparity between non-ACC and ACC respondents. This involved establishing if there were differences in employment, living status, health and well-being, physical activity, and social support profiles of people ageing with SCI in New Zealand between those people who received support from the Ministry of Health and ACC. A complex picture emerged with some respondents receiving support from both the Ministry of Health and ACC. A number of people indicated that they received income from a variety of sources, for example part-time work, ACC and earnings from investments. Funding for care and support could also come from more than one source with instances where the Ministry of Health and/or Ministry of Social Development and ACC were cited as funding sources. A participant could be on the invalid's benefit, unemployment benefit or receiving superannuation and at the same time be receiving funding support for care and equipment from ACC. Regarding current employment, the majority of participants did not respond, either because they chose not to or they did not have an occupation. The wording of the financial questions may have, in part, contributed to this complex picture. For example, in the question regarding sources of income over the previous 12 months respondents were asked to indicate the various ways they received income from a list of options, as well as an option for indicating other sources. If the question had been phrased to request the main source of income the response profile may have been easier to discern and analyse.

In regards to preferred employment, of those respondents receiving the invalid's benefit, none preferred to be receiving this, but 60% wished to be in part-time employment. This finding suggests the many participants' employment desires are not being met. Of those who were

receiving ACC, 46% declared that they preferred receiving ACC, 29% preferred part-time employment, and 17% preferred full-time employment. A possible option to improve the employment situation would be to undertake a complete review, including medical assessment, of people with long-term SCI at 20 years post injury. Those people who request it could be referred to appropriate vocational assessment professionals. Vocational assessment is available specifically for newly injured people with SCI such as the Kaleidoscope Programme run by the NZST which has been very successful at getting people back to work. People who have been injured for a number of years and have been unable to find regular employment should be able to seek referral to appropriate vocational assessment if they so wish, whether they are funded by ACC or the Ministry of Social Development.

Paul et al.(2013), in a longitudinal cohort study, followed 118 people (of which 91 completed the 30 month interview) admitted to the two spinal units in New Zealand between 2007 to 2009 to estimate the socioeconomic and work outcomes two and half years following SCI. They concluded that people on ACC retained their economic status and returned to work at a relatively high rate (54%). This is likely to be due to the combined effect of ERC, a focus on rehabilitation to work, and non-means tested support services. For those people not eligible for ACC, income fell to less than half the ACC group and the rate of return to work was lower (29%). This would tend to support the long-term potential benefits of ACC and the focus on getting people back to work.

In the Phase 3 study population the average age was 57 years (range: 28, 83 years) and time since injury was 31.6 years (range: 21, 59 years). The people who participated in this phase of the study had lived with SCI for a prolonged period and were people who had survived, adjusted and adapted their living circumstances to enable them to cope with their SCI. The distinction between those people funded by ACC and non-ACC sources possibly had the appearance of being less marked. In addition, 16% of the respondents were 65 years and older and were receiving New Zealand Superannuation. There were no significant differences between non-ACC and ACC participants in regards to rated standard of living, rated satisfaction with standard of living and income meeting everyday needs. Participants in the study population reported maintaining good social support networks and community involvement when compared to a similar age group of able-bodied people described in the HWR sample. Any distinction between ACC and non-ACC respondents was considered unlikely. The majority of respondents were participating in society, socially active, and

involved in family and community life at levels similar to the HWR study population. This may go some way to explain why there was little difference between people on ACC and non-ACC. Further focused research might establish more clearly whether there are differences between other population groups of disabled people who are receiving long-term Ministry Health and ACC funding.

Currently the ACC and Ministry of Health are jointly developing a Spinal Cord Impairment Initiative and Implementation Plan (Howard-Brown & Esplin, 2013). If successful the joint national implementation plan will improve the outcomes and promote increased independence and participation of people with spinal cord impairment, develop an integrated and sustainable approach to support people with spinal cord impairment meeting their goals, and provide a platform to implement new or update existing service models and technologies as appropriate and affordable (Howard-Brown & Esplin, 2013). It is anticipated that this joint initiative will go some way to improving service delivery to people with SCI.

8.4 Quality of life

From previous studies on ageing with SCI and QOL, it appears the longer someone lives with SCI the more likely they are to report overall QOL as good or excellent over time. In comparison, later onset of SCI is associated with lower QOL (Charlifue et al., 2004; McColl et al., 2004; Sakakibara et al., 2012). Better QOL is related to fewer health and disability related problems and active participation in the community especially employment, whereas lower QOL is related to gender (female), years post injury, multiple health problems combined with having a higher lesion and more disability related problems. It would seem that key ingredients to having a good perceived QOL are participation in enjoyable activities and a feeling of contributing to society to fulfil one's potential. Good social support systems and coping skills are crucial to coping with age-related changes in functioning (Albrecht & Devlieger, 1999; Geyh et al., 2012; Kemp et al., 2004; Krause & Broderick, 2005). Ginis et al. (2011) suggest that the loss of fitness and independence associated with physical inactivity can significantly influence the development of secondary conditions, overall QOL, and community participation. They believe it is important that physical activity is promoted to improve the health and fitness and overall QOL with people with SCI.

In general terms the majority of participants in the present study reported doing some exercise with a considerable number indicating they undertook regular exercise. Tetraplegics and/or

those aged 65 years and older were more likely to indicate they were not exercising. Ginis et al. (2011) have developed the first evidence-based physical activity guidelines for people with SCI. They suggest adults with SCI should engage in at least 20 minutes of moderate to vigorous intensity aerobic physical activity two times per week and strength training exercises two times per week, consisting of three sets of 8 to 10 repetitions of each exercise for each major muscle group (Ginis et al., 2011). They encourage people with SCI, clinicians, researchers and fitness programmes to adopt these guidelines that have been developed.

In the present study, of those people interviewed in Phase 1, the majority indicated that they had maintained good relationships and social interaction within the community. Relationships with family and friends were regarded as important, especially as people became older. These findings were reinforced in Phase 3 with the results clearly indicating that people were maintaining a high level of social support and networks especially with family/whānau and friends. Tetraplegics were almost four times and paraplegics twice as likely to rate their standard of living high or fairly high compared to SCI people who were walking. Those who were in a relationship were twice as likely to rate their standard of living high or fairly high compared to those not in a relationship.

Charlifue and Gerhart (2004) suggest that both people with disabilities and older people alter the criteria that serve as a yardstick against which they measure QOL. In order to enhance their self-esteem, happiness and their QOL, they devalue unattainable goals while increasing the value of things in which they can succeed. The concept, termed the 'disability paradox' (Abrechrt and Devlieger, 1999) attempts to explain this by suggesting those people with disabilities who rate their QOL as high or very high, obtain an understanding of their condition or disability and take control, introducing order and predictability in their lives. They learn what is possible, set goals, develop values that make sense of their disability, and search out resources to manage their lives better within their environment. They engage in social networks and give to and receive from others in reciprocal relationships. This rationale is similar to the concepts of the independent living movement (similar to rejection of disengagement theory in ageing) put forward by Gerben DeJong and promoted by Professor Alan Clarke in New Zealand (Cassidy et al., 2004; DeJong, 1979). Both the independent living movement and activity and continuity theory in ageing reject the behavioural expectations created by the sick role, the impaired role, or by ageism, by indicating that those people who are disabled or ageing do not want to be relieved of their family, occupational,

and civic responsibilities in exchange for a childlike dependency, but rather they wish to take control of their own lives. This includes managing their own affairs, participating in day-to-day life in the community, fulfilling a range of social roles, making decisions that lead to self-determination, and minimising physical or psychological dependence on others. In gerontology, subjective well-being has been thought to remain relatively stable into old age and not decrease as much as expected over time or with age. It has been defined as a broad concept comprising a wide range of distinct dimensions such as life satisfaction, positive affect, happiness, personal growth, satisfying social relationships, and autonomy (Kunzmann et al., 2000). The authors add that the term ‘paradox’ has been used in absence of a strong relationship between age and subjective well-being, despite an increase in risks and losses with advancing age. They suggest some dimensions of subjective well-being remained stable, while others decline, such as self-rated health. Such concepts are part of both the New Zealand Disability and Positive Ageing Strategies (Ministry of Health, 2001, 2002).

The development of such concepts as outlined above, assists to explain why in this study seriously disabled people such as tetraplegics were found to rate QOL positively. This can also be illustrated when the lifespan development theory and/or the life-course theory developed in gerontology are applied to adults ageing with SCI (Daatland & Biggs, 2006; Jeppsson Grassman & Whitaker, 2013; Molton & Jensen, 2010; Smith & Gerstorf, 2006). The lifespan development theory suggests that development occurs throughout a person's lifespan with individuals continuously adapting to external changes and demands which include the interaction of biological, social and psychological factors. Key to the lifespan theory and life-course theory is the concept of successful ageing, with people considered to have aged successfully when they are able to continue to perform tasks that are personally meaningful and important, despite any decline in skills, memory and performance. This means that ageing is a very individual experience whereby each individual can and most likely will experience ageing differently whether they have a disability or not (expanded on in section 8.5). Such theoretical concepts fit well with why, as in this study, subjective QOL can be rated positively but can also explain why many people ageing with SCI cope well with the development of secondary conditions, and continue to have active and full lives. It could also be relevant that many people ageing with SCI have lived with their disability for a long time. During that time there would have been stages and events in life (e.g. getting married and/or having children) where a review, evaluation, and resetting of life expectations and goals would have been

undertaken and planned for. Those people who are ageing with SCI may potentially have a unique personality type and be people that tend to have a more positive outlook on life. Or a positive outlook on life may develop over time after the injury as people realise they have a second chance at life and all that it still has to offer.

Ubel et al. (2005) suggest any people with chronic illness and disability adapt to their circumstances. This includes adapting the environment that they live in and/or adapting psychologically by shifting their goals and priorities in life. They reduce their expectations to live within the domains that they can accomplish. They find meaning and purpose and other aspects of their lives re-define what it means to be happy. They also suggest if ‘healthy’ people do not take this adaptation process into account or underestimate its power, then they are bound to have overly pessimistic predictions about illness and disability, further contributing to the disability paradox and to ageist expectations. They conclude that people who experience a wide range of illnesses and disabilities often report paradoxically high levels of QOL and mood. Many ‘healthy’ people are sceptical that such self-reports are credible as they predict that they would not be the same under similar circumstances, yet the reality seems different.

8.5 The life-course and diversity of ageing with SCI

The number of people ageing with disabilities is growing in association with an ageing population worldwide. Older people are more at risk of experiencing chronic health conditions, and so there is a global increase in people experiencing disability. Disability trends vary across countries and are influenced by population health status and environmental factors. People with disabilities experience poorer levels of health than the general population, and have more likelihood of developing preventable secondary conditions, co-morbidities and age-related conditions, yet at the same time are living much longer into old age (World Health Organization, 2011a, 2011b, 2013a).

Reported incidence rates of SCI vary considerably ranging from a relatively low 10.4 per million to a relatively high rate of 83 per million (van den Berg et al., 2010; Wyndaele & Wyndaele, 2006). Any analysis of trends and inter-country differences would benefit from the development of a universally accepted way of collecting and classifying SCI data. Improving the reliability of data needs to include the use of a clear definition of SCI which covers both traumatic and non-traumatic conditions.

The American Spinal Injury Association's Standard Neurological Classification of Spinal Cord Injury (Waters et al., 1991), commonly referred to as the ASIA assessment, is the most widely accepted diagnostic assessment tool used by spinal specialists for defining the neurological level of SCI. When the SCI is recorded and classified on a DHB's PIMS or the Ministry of Health's PIMS an alternative classification or coding system may be used (such as the internationally used ICD-10 coding system). This is especially relevant when traumatic and non-traumatic SCI diagnosis may be classified differently. For example if someone sustains SCI paralysis from a cancerous tumour it would be firstly classified as a cancer-related condition. It would greatly benefit New Zealand and international research and service planning if a universally agreed way of classifying SCI was used and a national spinal register was established to keep track of people with SCI. A New Zealand register would enable regular contact with SCI people, provide the means to easily arrange periodic medical reassessment and be useful for research and associated development of an evidence base for service improvement. The current database with appropriate ethical approval could potentially be used to contribute to the development of such a register in New Zealand. A good example of a successful register is the New Zealand Cancer Registry which is a population based tumour registry with the primary function of collecting and storing cancer incidence data which provides information for survival studies, public health research, monitoring screening programmes and policy formulation. Information has been collected since 1948, however became a legal requirement with the passing into legislation of the *Cancer Registry Act 1993* (Ministry of Health, 2014).

It has been suggested that life expectancy after SCI is approximately 85% to 90% of that of non-disabled people, depending on the degree of neurological impairment and the age at the onset of injury (Capoor & Stein, 2005). Clinicians and researchers working in the field of ageing with SCI often refer to people with SCI as 'prematurely ageing' or having 'accelerated ageing' similar to that described among polio survivors and persons with other chronic disabling conditions (Adkins, 2004; Capoor & Stein, 2005; Kemp et al., 2004). This concept is based on biological deterioration of the body due to either the impact of the SCI or living with the SCI (or both) speeding up age-related biological deterioration. A wide range of factors can affect this biological decline such as paramedic or medical care immediately following injury, neurological level, extent and duration of injury, age at time of injury, weight, pre-injury health history, medical comorbidity, gender, ethnicity, success of

rehabilitation at time of injury, alongside a complex interaction of genetic factors, lifestyle, adaption to stress and social roles, alterations in living situation and family structure, and potential depletion of social and economic resources (Adkins, 2004; Capoor & Stein, 2005; Kemp et al., 2004).

There is enough evidence from longitudinal research studies that indicates that people who incur their SCI when young adults or middle aged go through a period of relative stability of between 20 to 25 years post injury before starting to develop a variety of possible secondary conditions. This was found to be case in Phase 1 of the present study with many participants interviewed indicating that they were incurring secondary conditions such as musculoskeletal issues, skin care, fatigue, bowel and bladder issues. The development of these secondary conditions was influencing social interaction and lifestyle choices. How these secondary conditions are identified and managed by the individual and medical specialists is an important part of how individuals with SCI manage their lives from that time on. A crucial factor in this scenario is the younger a person is when they originally sustain their SCI; the earlier in their life-course they are likely to encounter the possible development of secondary complications.

The other major cohort who will have an impact on medical and social support services are those people who sustain SCI at an older age. With the expectation that the worldwide population 65 years and older will double over the next 40 to 50 years, it is anticipated that there will be an increase in the incidence of non-traumatic SCI as well as an increase in traumatic SCI mainly due to falls by people 60 years and older (Burt, 2004; Ho et al., 2007; Jackson et al., 2004; van den Berg et al., 2010).

Biological deterioration is part of the ageing process and happens to all people regardless of whether or not they have a disability. However biological deterioration is a very individual experience and has no clear timetable and depends on many accumulating factors such as ethnicity, type of disability, genetics, personal health, external environment as well as social integration and adjustment to name a few. Jeppsson Grassman and Whitaker (2013, p 4) suggest that “the meaning of a person's disability is best understood in the context of the *dynamics of the whole life-course* and with an approach in which *ageing is seen as a lifelong process*”. They add that this life-course approach contributes to illuminating the considerable variation in people's experiences over time, due to differences in individual resources and positions as well as there being shared experiences. Following this reasoning people with SCI

(and disabled people generally) may share specific experiences yet also have a wide range of different experiences and complications that will affect their individual life-course.

In many countries rehabilitation programmes have frequently assumed that once someone has been rehabilitated and reached maximum functional ability that there is no need to worry about the additional consequences associated with further decline brought about by worsening complications (Jeppsson Grassman & Whitaker, 2013). Time since sustaining the original injury or condition is a key component of when someone with SCI or other type of disability is likely to develop a secondary condition (Adkins, 2004; Capoor & Stein, 2005; Groah et al., 2012; Jeppsson Grassman & Whitaker, 2013; Kemp, 2004). As discussed earlier in section 8.2, in the present study, time since sustaining the original injury was not found to be a significant factor.

Rather than considering people with SCI to be ‘prematurely’ ageing, it is more appropriate to suggest that they are experiencing what all people with disabilities and able-bodied people generally experience over their life-course: ageing, but in diverse ways. This diversity is part of the human condition and general life-course whereby people all face physical, functional, psychological, social and environmental changes with ageing. As people age, regardless of whether they are able-bodied, have SCI, or another type of disability, there is a need to constantly re-evaluate and adjust as health, environment and social circumstances change. The ability to cope and adapt to these changes varies considerably with individuals’ ability to re-evaluate and change, which some people may find difficult. Jeppsson Grassman and Whitaker (2013) sum it up by suggesting that a person’s life-course is complex, involving time with a disability, age, ‘time left’ and relational time which are all interwoven in complex functional loss. They go on to suggest that people with physical disabilities can, through environmental adjustments and personal assistance, live outgoing and ‘public lives’ into old age. For many, however, there is the invasive reality of the physical disability or illness that simply makes such a life experience impossible and out of reach. This challenges key principles about both successful ageing and the dominant norms about what life with disability ‘ought to be’ and the reality of how it is for many.

8.6 The future

As the number of people ageing with SCI increases, it becomes a dynamic and rapidly evolving field both practically and conceptually. It can be anticipated that the information and

knowledge gained from international longitudinal research studies about the long-term implications of living with SCI will be reflected in more appropriate medical and support services for people ageing with SCI (Charlifue, 2007; Krause & Broderick, 2005). Ongoing longitudinal studies will provide further insight into how people manage SCI into old age and the relevance of time since injury, development of secondary conditions and the impact of innovation and improvements in medical knowledge and technology. Recently the World Health Organization, in collaboration with the International Spinal Cord Society, published a comprehensive report that reviewed the status of SCI worldwide (World Health Organization, 2013b). A key finding was that between 250,000 to 500,000 people annually incur SCI, the majority of which are caused by preventable causes such as the MVA, falls or violence. People with SCI were two to five times more likely to die ‘prematurely’ than people without SCI, with the worst survival rates being in low and middle income countries. SCI was associated with lower rates of school enrolment and economic participation, and carried substantial individual and societal costs (World Health Organization, 2013b).

In New Zealand there has been an increase in specific research on people with SCI. Dunn (2012), in a doctoral thesis, researched the decision-making process of people who sustained cervical SCI and were eligible for upper limb reconstructive surgery; Paul et al. (2013) looked at the socioeconomic and work outcomes two and half years following SCI and compared those in receipt of ACC and those not. Dunn et al. (2014) evaluated the effects of ageing on hand function among patients with tetraplegia who had forearm tendon transfer surgery between 1982 and 1990, and the present study has looked at people ageing with SCI. Also the joint ACC and Ministry of Health’s Spinal Cord Impairment Initiative and Implementation Plan has reviewed the current services provided to people with SCI in New Zealand and made recommendations on ways of improving the services (Howard-Brown & Esplin, 2013). If fully implemented there is the potential to improve coordination and service provision of medical and support services for people with SCI.

There will be an increasing number people ageing with SCI who are currently users of disability related services (ACC, DHBs, Ministry of Health and/or Ministry of Social Development) but who, at age 65 years, will become users of age-related services managed essentially by the same organizations but under different criteria and with different services. How this new cohort of people ageing with SCI and their developing complex secondary conditions, as well as an increasing number of older people sustaining SCI, will affect the

medical and social support services for the older age groups is unclear. Planning needs to begin now regarding how these new cohorts of those ageing with SCI and other disabilities will transition into the care of older people's services. Those ageing with SCI will still require specialised SCI care and review to manage the specific secondary conditions that they may develop.

To sum up, New Zealand medical and social support services will need to recognise and respond to a growing ageing SCI population. This group will develop a range of complex circumstances, including gradual social, physical and functional loss combined with the development of secondary conditions which may occur at any time over a person's life-course, but are more likely as they get older. These issues not only relate to people with SCI but also to all people with disabilities, as they age.

8.7 Limitations of research

While the mixed methods study has many salient strengths and considerable care was applied to multiple facets, weaknesses and biases nonetheless potentially affect the resultant findings. For those people who took part in the study, when they had their injury has influenced how they have aged with their SCI. There have been major advances in medical knowledge, support, technology and society over the time that many of the sample sustained the SCI. The sample cohort is a mix of heterogeneous individuals which potentially affects the generalisability of the study's findings.

Phase 3 was a cross-sectional study whereby the data was collected at a single point in time. It allows associations between age, and time since injury and adjustment at a given point in time to be measured (DeVivo, 2004), but it does not indicate how adjustment changes over time or how environmental changes affect adjustment. Causality can sometimes be difficult to resolve, potentially causing ambiguity (Koepsell & Weiss, 2003). The data exposures and outcomes were collected simultaneously with specific inclusion and exclusion criteria being established (Koepsell & Weiss, 2003). Inclusion criteria included: incurring SCI before 1 January 1990 which has affected a person's mobility or neurology; having been admitted at some stage to either the ASRU or BSU; and having a NHI number and current contact details on the Ministry of Health's PIMS. Exclusion criteria included: not currently residing in New Zealand; being resident in New Zealand but non-English speaking; or being deceased. The doctoral thesis had limited financial resources and it was impracticable to recruit translators

for a likely minimal number of non-English speaking respondents. It was recognised that there were limitations associated with identifying people ageing with SCI through the Ministry of Health's PIMS. The information is only as reliable as the last time the person came in contact with a hospital using the Ministry of Health's PIMS and their contact details were updated. If someone had not been in hospital for many years and had shifted from the address last logged on the relevant PIMS the person's contact details would not be correct therefore making them difficult to contact. This was found to be the case with 136 (13% of total 1042) envelopes being 'returned to sender'. It is unclear what influence this may have had on people not responding. It would be anticipated that people with major SCI such as tetraplegics would come in contact with the health system relatively frequently and that their addresses would be up to date. Possibly, though, paraplegics and those people with SCI who were walking may not be frequently in contact with health services.

In a cross-sectional study the sample size should be sufficiently large both to represent the target population and to estimate the prevalence of variables of interest (Hennekens & Buring, 1987; Koepsell & Weiss, 2003). Although there were statistically significant differences in age and time since injury between the 284 respondents and 614 non-respondents, on a practical level these mean differences were relatively small and unlikely to substantially bias any results. This, coupled with the similarity in age at injury and gender profiles of the respondents and non-respondents, suggests that the respondents who completed the questionnaire are likely to be broadly representative but some important non-sampling biases may exist. However the sample captured a diverse group of people and the findings are likely to be generally representative of people living with SCI incurred before 1 January 1990 in New Zealand.

Some questions were ambiguously written and so could not be included in the analysis. In Section 3 Health & Disability, questions 13 to 16 used the WHO's AUDIT-C to establish how much and how often respondents had a drink containing alcohol. Despite thorough review by the supervisory team and external bodies, it was discovered after the questionnaire had been distributed that there was a typing error in question 14 which had the potential to misdirect how respondents answered questions 15 and 16. Respondent responses to these questions were not included in the results and it also meant the AUDIT-C could not be scored as originally intended. In Section 4 Physical Activity, the NZFPAQ-Short Form developed by Sport and Recreation New Zealand was slightly modified to better suit the SCI population.

Respondent responses to question 1 of the NZFPAQ-Short Form when analysed showed major variation indicating that respondents may have misinterpreted the question. Therefore the results to the question were not included in the final results.

In Section 1 Background Information, a high percentage (58.1%) of the sample did not respond to question 21 regarding occupation either because they did not have an occupation or declined to answer. It also highlighted the ambiguous nature of the question. This limited the statistical analysis that could be undertaken with this variable as it was likely there would be inherent biases which would affect results. It was anticipated that question 25 which asked respondents to indicate all the ways they received income over the previous 12 months would provide information that indicated those who received ACC or were on a government benefit (i.e. unemployment, invalid's benefit). In reality the question provided valuable information about income sources but did not provide clear information about those who primarily received ACC support and who did not. What it did highlight was that the sources of income and support were more complex than anticipated and not easily defined. The demarcation between those who received ACC and/or another government benefit could have been better defined by including a question that asked clearly whether respondents received ACC's ERC or were on another government benefit such as the unemployment or invalid benefit.

The research study may have benefited from more specific questions that related to SCI, such as the types of secondary conditions that individuals were incurring. These could have been listed or the question left open. Also it could have been insightful to have developed a series of questions that related specifically to people getting older and whether their experiences were related specifically related to ageing or connected with living long-term with SCI. The questionnaire was already relatively long and it was recognised that additional questions could make the questionnaire over-long and potentially affect response rate.

8.8 Recommendations

The following recommendations for New Zealand are listed under three headings Research, Policy and Service needs. Under Service needs, some recommendations are general recommendations rather than specifically related to the research.

Research

It is recommended that:

1. There is more specific research undertaken to establish whether there are significant long term differences between people with SCI (and specific populations of disabled people) who receive funding from the Ministry of Health and ACC.
2. High priority is placed on establishing mutual agreement among the key stakeholders (i.e. spinal specialists, ACC, Ministry of Health, DHBs, health researchers and government policy makers) to undertake appropriate research to develop a national register of people with SCI.
3. That this research into developing a spinal register uses a universally agreed way of classifying SCI.
4. There is research devoted to investigating the implications of people ageing with SCI who, as they become 65 years old, move from disability-related support services to the responsibility of age-related support services that cater for the care and support of older age groups.

Policy

It is recommended that:

1. Priority be given by appropriate government departments to ‘high level’ thinking and policy planning that will ensure that the growing new cohorts of people ageing SCI and other disabilities that are currently the responsibility of disability related support services transition smoothly to the responsibility and care of the older age group support services.
2. Policy planning recognise that people ageing with SCI will require regular periodic specialised SCI review and care to manage specific secondary conditions as they develop.
3. Such ‘high level’ thinking and policy planning takes into consideration the goals outlined in both the New Zealand Disability Strategy and the Positive Ageing Strategy.

Service needs

It is recommended that:

1. Specialised SCI acute and post-acute medical and rehabilitation services be aware of the changing demographic trends and respond appropriately. This includes catering for an increasing number of ageing people with SCI and associated secondary conditions. At the same time there will be an increasing number of people who sustain SCI at an older age and require specialised rehabilitation treatment and protocols that reflect their age.
2. There are appropriate guidelines and systems in place to enable each SIU to identify past patients at approximately the 20 year post injury period to offer them a medical reassessment to identify potential secondary conditions associated with SCI before they develop into major health issues. From that point on there should be periodic review and monitoring.
3. As mentioned under '*Research*' a national SCI register needs to be established and maintained to record appropriate details on all people with SCI. This would assist with identifying people when they reached the 20 year post injury period and assist with future research into SCI.
4. More is done to identify those people ageing with SCI who are currently or potentially isolated and lonely and assist them to make contact with appropriate Family and Peer Support Programmes run by NZST and TASC as proposed by the SCI Initiative and Implementation Plan or alternative community programmes.
5. Specific health promotion guidelines for people ageing with SCI need to be developed which can be circulated amongst the SCI community.
6. Adults with SCI should engage in at least 20 minutes of moderate to vigorous intensity aerobic physical activity two times per week and strength training exercises two times per week, consisting of three sets of 8 to 10 repetitions of each exercise for each major muscle group (Ginis et al., 2011).
7. The recommendations from the final joint ACC and Ministry of Health Spinal Cord Impairment Initiative and Implementation Plan (2014) are introduced.

8.9 Conclusion

The aim of this thesis has been to redress an information deficit and to develop a better understanding of the health, living circumstances and QOL of people ageing with SCI in New Zealand. This has involved gaining an understanding of international and New Zealand demographic trends, theories and literature on ageing and disability. It has also included developing an understanding of the political activism of disabled and older people, as well as the development of relevant key New Zealand government policies and strategies. The insight and understanding gained confirmed that there is a new demographic phenomenon occurring worldwide and in New Zealand of an increasing number of people who are either born with or who sustain a physical disability when young or middle-aged, who are ageing with the disability and often develop secondary conditions.

The present research study uncovered a 'hidden population' of people ageing with SCI, with more people than anticipated being discovered and included in the SCI database. As the actual number of people ageing with SCI in the community was unknown, it has been rewarding for all those people involved in the research to discover such a large number of people ageing with SCI, with the majority living full and active lives and contributing to the community. This has particular relevance for those people who incurred SCI in the 1960s who had to overcome major obstacles on a daily basis with no or little government support, including having to purchase their own wheelchairs. Such hardship amongst people with SCI and the wider disabled community led to political activism which eventuated in the development of major changes in governmental disability support with the introduction of ACC in April 1974 and the Disabled Persons Community Welfare Act in 1975.

The findings in the present study are consistent with the phenomenon of the 'disability paradox' (Abrechrt and Devlieger, 1999). Many tetraplegics seemingly have grasped this powerful concept by successfully taking control of their destiny and introducing order and predictability in their lives. This has empowered them to carry on living, getting the most out of life and yet recognising the limitations of their circumstances. It reinforces people's desire to reject the sick role and bring a level of normality into their lives whereby they can set goals and make sense of living with their disability. Such a rationale can potentially be applied by able-bodied people as they age and need from time to time to re-evaluate their goals and life course. New Zealand medical and social support services will need to recognise and respond to an increasing number and diverse range of people ageing which will include people with

SCI, people with other disabilities and able-bodied people in general, recognising that there will be often a wide range of complex interwoven issues needing to be monitored. These include gradual social, physical and functional loss combined with the development of various secondary conditions which may occur at any time over a person's life-course, but are more likely to occur as they get older. It is part of the human condition that people age whether disabled or not. There are shared experiences yet also a wide range of different experiences and complications that affect an individual's life-course, making each individual's life journey truly unique.

Glossary

Accident Compensation Corporation: No fault, 24-hour cover compensation scheme in New Zealand that compensates people who sustain a personal accident by injury by providing 80% of their previous year's earnings for the length of time they are unable to work following their injury, as well as covering medical and care expenses relating to the injury.

Activities of daily living: Activities that are normally performed during a normal day, including any daily activity we perform for self-care (such as feeding, bathing, dressing, grooming), work, homemaking, and leisure.

District Health Board: Organizations in New Zealand established to protect, promote and improve the health and independence of a geographically defined population. Each District Health Board funds, provides, and ensures, the provision of services for its population.

Māori language used:

Koroua be old, elderly man, male elder

Kuia elderly woman, female elder

Māori indigenous people of New Zealand

Whānau extended family and family group which may include friends

Paraplegia: Injury or disease to the thoracic, lumbar or sacral level resulting in impairment and loss of motor and sensory function of the trunk, legs and pelvic organs.

Quality of life: The congruence between aspirations and accomplishments, as perceived by the person involved. It is influenced by: health and personal safety, independence, the ability to earn and income, access to material comforts, the ability to have and raise children, the likelihood of developing a close relationship with a member of the opposite sex or a close and supportive network of friends (Dijkers, 1997).

Spinal cord injury (SCI): Occurs when there is damage to the spinal cord as a result of trauma or disease (i.e. neoplasms, vascular disease). The damage to the spinal cord blocks communication between the brain and body. Injury to the spinal cord at the cervical level results in tetraplegia, injury to the thoracic, lumbar or sacral level results in paraplegia. This results in muscular weakness, paralysis, loss of sensation, loss of bowel, bladder and sexual function that is dependent upon the level and severity of the damage.

Tetraplegia: An injury or disease occurring to the cervical spinal cord that results in impairment and loss of motor and sensory function of the trunk, arms, legs and pelvic organs.

Walking SCI: An injury or disease that causes incomplete impairment and loss of motor and sensory function. Often the person with incomplete SCI can partially walk or walk relatively normally however still have complications relating to SCI such as sensory, bladder, and bowel issues.

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Appendices

- Appendix 1 Approval letter from the Upper South A Ethics Committee (URA/07/04/026)
- Appendix 2 Letter from the NZST signed by the Trust's CEO,
Summary Information Sheet, Consent Form and Permission Slip
- Appendix 3 Letter thanking participants for taking part in the research study and a
summary of key findings
- Appendix 4 Multi-regional ethics Committee application MEC/09/06/061 approval letter
- Appendix 5 Questionnaire
- Appendix 6 Multi-regional ethics Committee application MEC/11/01/002 approval letters
- Appendix 7 Spinal Network News article in the May 2011 issue
- Appendix 8 Letters of introduction from two spinal units
- Appendix 9 Summary Information sheet and Consent form

Appendix 1 Approval letter from the Upper South A Ethics Committee (URA/07/04/026)



10 July 2007

Upper South A Regional Ethics Committee

Ministry of Health
4th Floor, 250 Oxford Terrace
PO Box 3877
Christchurch
Phone (03) 372 3037
Fax (03) 372 1015

Mr Richard Smaill
Department of Public Health and General Practice
University of Otago
P O Box 4345
Christchurch

Dear Mr Smaill,

The implications of ageing with a physical disability**Investigator: R Smaill****Ethics ref: URA/07/04/026**

The above study has been given ethical approval by the **Upper South A** Ethics Committee. A list of members of this committee is attached.

Approved Documents

Information sheet and consent form version 2 dated 21 May 2007

Certification

The Committee is satisfied that this study is not being conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the trial is being carried out.

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.

Final Report

The study is approved until 15 September 2007. A final report is required at the end of the study. The report form is available on <http://www.newhealth.govt.nz/ethicscommittees> and should be forwarded along with a summary of the results. If the study will not be completed as advised, please forward a progress report and an application for extension of ethical approval one month before the above date.

Requirements for SAE Reporting

The Principal Investigator will inform the Committee as soon as possible of the following:

- Any related study in another country that has stopped due to serious or unexpected adverse events
- withdrawal from the market for any reason
- all serious adverse events occurring during the study in New Zealand which result in the investigator or sponsor breaking the blinding code at the time of the SAE or which result in hospitalisation or death.
- all serious adverse events occurring during the study worldwide which are considered related to the study medicine. Where there is a data safety monitoring board in place, serious adverse events occurring outside New Zealand may be reported quarterly.

All SAE reports must be signed by the Principal Investigator and include a comment on whether he/she considers there are any ethical issues relating to this study continuing due to this adverse event. If the adverse event is local and does not have the sponsor's report attached, an opinion on whether the event is thought to be related to the study should be given along with any other pertinent information. It is assumed by signing the report, the Principal Investigator has undertaken to ensure that all New Zealand investigators are made aware of the event.

Amendments

All amendments to the study must be advised to the Committee prior to their implementation, except in the case where immediate implementation is required for reasons of safety. In such cases the Committee must be notified as soon as possible of the change.

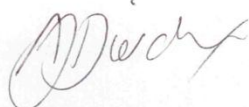
Please quote the above ethics committee reference number in all correspondence.

The Principal Investigator is responsible for advising any other study sites of approvals and all other correspondence with the Ethics Committee.

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



Alieke Dierckx
Upper South A Ethics Committee Administrator

Email: alieke_dierckx@moh.govt.nz



Upper South A Regional Ethics Committee

Ministry of Health
4th Floor, 250 Oxford Terrace
PO Box 3877
Christchurch
Phone (03) 372 3037
Fax (03) 372 1015

List of members of the Upper Region A Ethics Committee, April 2007

Carolyn Mason (Chair)	Ethicist/Philosopher Lay member	Female
Carolynn Bull	Legal representative, Maori representative Lay member	Female
John Horwood	Biostatistician Lay member	Male
Jane Kerr	Researcher Health Professional Member	Female
Alison Luckey	Health Practitioner Health Professional member	Female
Tom Marshall	Clinical Psychologist Health Professional member	Male
Ellen McCrae	Pharmacist Health Professional member	Female
Edie Moke	Maori representative Lay member	Female
Nicky Murray	Community Representative Lay member	Female
Elizabeth Richards	Consumer Representative Lay member	Female
Russell Scott	Health Practitioner Health Professional member	Male

Jane Kerr, Russell Scott and Carolyn Bull were not present at the meeting on 30 April 2007.
Sharon English, Health Practitioner, attended as an expert advisor.


Alieke Dierckx (Administrator)

10/02/2007
Date

Appendix 2 Letter from the NZST signed by the Trust's CEO,
Summary Information Sheet, Consent Form and Permission Slip

Dear (name)

RE: Research Study on the Implications of Ageing with a Physical Disability

The New Zealand Spinal Trust has been asked to support and assist with a research project being undertaken by Richard Smaill, a PhD student who is researching the implications of ageing with a physical disability. Many of you may know Richard as he has been a tetraplegic himself for 33 years.

The New Zealand Spinal Trust fully supports this research project as it believes this is an important topic and information gained from the research study has potential to benefit spinal cord injured people. It will assist with gaining important information about the requirements and needs for those ageing with a spinal cord injury.

To collect some preliminary information Richard wants to interview 10 spinal cord injured people who have been injured longer than 25 years. To assist Richard in contacting people, the trust is writing to you to introduce Richard and enquire as to whether you would be interested in taking part in the research study. Enclosed with this letter is a detailed summary information sheet prepared by Richard that explains the research project in detail. The Research Project has full Ethics Committee approval.

After reading the information sheet, could you please indicate "Yes" or "No" on the enclosed permission slip as whether you are happy for the NZST to pass on your contact details to Richard. Richard will then contact you directly to give you more information and, if you agree to be interviewed, to arrange a time to undertake the interview. You may, of course, change your mind about being interviewed at any time.

Yours sincerely

.Andrew Hall
Chief Executive
New Zealand Spinal Trust

Summary Information Sheet for Interviewees

Project: Implications of Ageing with a Physical Disability

Researcher: Richard Smaill, PhD student

Supervisor: Associate Professor Pauline Barnett

Department: Public Health and General Practice, Christchurch School of
Medicine and Health Sciences, University of Otago

Why investigate disability and ageing?

In the last 40-50 years a new sub-group has emerged within society, people with moderate to severe disabilities. This has come about due to increased life expectancy and survivorship of such people through improved medical care and knowledge about caring techniques. Already, as this group ages, issues are arising about how resources can be allocated appropriately and expanding needs met. It is the overall aim of the proposed study to analyse the issues posed by this development both for policy makers and for the people themselves. With the ageing of the “baby boomer” population starting to impact on our society, equally so will the ageing disabled impact on our society’s social services and health system. It appears that government, government agencies and society generally have failed to recognise or appreciate the impact that the ageing disabled will have on our social services and health system. It is important that information is collected and policy issues are discussed regarding the impact that the ageing disabled may have.

It is recognised, from both international and NZ evidence that there is:

- (i) pressure on health and disability resources
- (ii) rising expectations based on new technology and human rights.

Given these trends, the issue of ageing with disability will become increasingly important. This affects two groups of people with disabilities, those who are;

- Ageing with life-long or early-onset disabilities, such as polio, cerebral palsy, and multiple sclerosis, spinal injury, head injury, mental illness, intellectual handicapped, and those
- Surviving with mid to later-life onset of disability, such as stroke and disability.

What are the specific aims of the study?

1. To gain insight and learn about the issues and challenges facing a group of spinal cord injured people in New Zealand. This information can be compared with the considerable international literature on ageing with a spinal cord injury.
2. To use the knowledge gained from the interviews and referring the international literature to develop a more comprehensive research project. This will potentially include interviews with;
 - other spinal cord injured persons,
 - people with other types of disabilities,
 - health and medical specialists,
 - social service agencies,
 - funding agencies, and
 - policy planners.

What does the present interview involve?

It is intended to carry out 10 confidential individual interviews with a sample of spinal cord injured persons who have been injured 25 years or longer.

A key aim of the interview is to identify the major issues facing spinal cord injured people as they get older. It is anticipated that from this preliminary investigation valuable information will be gained to assist with developing a more comprehensive research project.

It is anticipated each interview will take between one to one and half hours to complete. The interview will be carried out at a convenient time and place for the interviewee.

You are free to withdraw from the interview at any time, or to decline to answer any particular questions in the interview.

The interview, if the participant agrees will be tape recorded to enable the researcher to refer to it at a later date, and to ensure accuracy of the information obtained.

Each interview will be summarized and returned to the interviewee to give each person the opportunity to check the interview summary for content and accuracy.

The individual interview summaries will then be collated into a general summary identifying the key issues that are identified from the interviews. Anonymity of the individual interviewees will be ensured and given the highest priority.

What happens to the information obtained and/or recorded during the interview?

All individual interview information will remain confidential and only be available to the researcher and his immediate supervisor, Associate Professor Pauline Barnett. All tape recorded material and identifiable written material will be securely stored in a locked cabinet in the Department of Public Health and General Practice. This stored information will be kept up to 10 years, where after it will be physically destroyed.

Individual interviews will be summarised and returned to the interviewee to enable them to read, comment on and check for accuracy.

The individual interviews will then be collated and summarised to identify the key issues identified by the interviewees. This will be done in a way which does not identify individuals. This summarized information may become part of a published research paper at a later date.

Information collected for the purposes of this interview may be used as part of the researcher's larger research study into the implications of ageing with a physical disability.

Further Information or Queries

Please contact Richard Smaill (mobile 0274 356 711) or his supervisor Ass Prof Pauline Barnett, at the Dept of Public Health & General Practice Christchurch School of Medicine & Health Services, University of Otago. P.O. Box 4345 Christchurch. Telephone 364-3628.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent Health and Disability Advocate, as follows:

South Island 0800 377 766

Free Fax (NZ wide) 0800 2787 7678 (0800 2 SUPPORT)

Email (NZ wide) advocacy@hdc.org.nz

Thank you for your cooperation and participation in this study

CONSENT FORM

Project: **The Implications of Ageing with a Physical Disability**

Researcher: **Richard Smaill, PhD Student**

1. I have read the Information Sheet for this study and have had details of the study explained to me.
2. My questions about the study have been answered to my satisfaction, and I understand that I may ask further questions at any time.
3. I understand that I am free to withdraw from the interview at any time, or to decline to answer any particular questions in the interview.
4. I agree to provide information to the researcher under the conditions of confidentiality set out on the information sheet.
5. I wish to participate in this study under the conditions set out in the Information Sheet.
6. I understand that when the interviews have been completed and the results collated, that I will receive from the researcher a summary of the general trends and results.
7. I consent / do not consent to the information collected for the purposes of this interview to be used as part of the researcher's larger research study into the implications of ageing with a physical disability. (Delete what does not apply)
8. I understand that if I have any queries or concerns at any stage I can contact Richard Smaill (mobile 0274 356 711) or his supervisor Ass Prof Pauline Barnett, at the Dept of Public Health & General Practice Christchurch School of Medicine & Health Services, University of Otago. P.O. Box 4345 Christchurch. Telephone 364-3628.
9. I understand that if I have any queries or concerns regarding my rights as a participant in this study, I may wish to contact an independent Health and Disability Advocate, as follows:

South Island 0800 377 766

Free Fax (NZ wide) 0800 2787 7678 (0800 2 SUPPORT)

Email (NZ wide) advocacy@hdc.org.nz

Participant's Name: _____

Participant's Signature: _____

Date: _____

Contact details: _____

Researcher's Name: Richard Smaill

Researcher's Signature: _____

Appendix 3 Letter thanking participants for taking part in the research study and a summary of key findings

Christchurch

1 October 2008

Dear

RE: Preliminary results from 12 interviews undertaken with people who had been injured from 26 to 50 years with a spinal cord injury

Enclosed with this letter is a summary of the information obtained from the interviews that you took part in late in 2007 and early 2008. I think you will agree after reading the summary information that there is some very insightful and useful information about how people in New Zealand are dealing with the issues of ageing with a spinal cord injury.

I really appreciate the time you gave to be interviewed and review your transcripts, to take part in the research study. Your frank and honest comments about your experiences with dealing with your spinal cord injury over a long time has given me invaluable information to assist with planning the next stage of my PhD research into the implications of having a physical disability and ageing.

In November I will be presenting a 10 minute condensed version of the summary at the Australian New Zealand Spinal Cord Society (ANZSCoS) conference to be held in Christchurch.

If you have any queries or questions regarding the information in the summary please do not hesitate to contact me (mobile 0274 356 711) or my supervisor Associate Professor Pauline Barnett at the Dept of Public Health & General Practice Christchurch School of Medicine & Health Services, University of Otago. P.O. Box 4345 Christchurch. Telephone 364-3628.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent Health and Disability Advocate, as follows:

South Island 0800 377 766

Free Fax (NZ wide) 0800 2787 7678 (0800 2 SUPPORT)

Email (NZ wide) advocacy@hdc.org.nz

Thank you once again for taking part in the study.

Yours sincerely

Richard Smaill

PRELIMINARY RESULTS FROM THE QUALITATIVE ANALYSIS OF INTERVIEWS WITH 12 SPINAL CORD INJURED PEOPLE WHO HAVE BEEN INJURED BETWEEN 26 TO 50 YEARS

Executive Summary

Methodology

Procedure

A group of spinal cord injured people who were identified as having been injured longer than 25 years were approached by the New Zealand Spinal Trust to ask whether they would allow their personal contact details to be passed on to the researcher. Enclosed with the letter from the New Zealand Spinal Trust was an information sheet which outlined the reasons for and aims of the research, what was involved in taking part and what would happen to the information that was collected. Of the 15 people approached, 12 agreed to be interviewed, one person declined, one person failed to respond, and one person failed to respond as a result of an unexpected death.

Those who agreed to be contacted by the researcher were telephoned to arrange a mutual time for the researcher to interview the person. This was usually arranged to take place at the person's home. Interviewees were given another copy of the information sheet, a schedule of the interview questions and a consent form to sign. The interviews usually took between one to one and half hours and were recorded. The recorded interviews were subsequently transcribed and either sent back to the interviewee by e-mail or mail to check for accuracy and to ensure they were comfortable with the content. Once the interviewee had checked the transcript it was returned to the researcher. The 12 interviews were undertaken from the 5th Sept 2007 to 12 March 2008.

The researcher undertook a thematic qualitative analysis of the interviews whereby the information from the interviews was classified under nine general themes.

1. The initial impact of the injury.
2. Issues associated with having a SCI a long time.
3. Specific issues associated with getting older.
4. The key issues likely to be encountered in the future.
5. Has life with your injury turned out the way you thought it might?
6. What sort of things in the past could have helped?
7. The impact of technology and changes in medical knowledge and treatment.
8. How a person's own experiences and knowledge has helped them and others.
9. Impact of a person's cultural background.

Analysis was completed on the 5 August 2008.

Subjects

The 12 people interviewed, 10 were male and two female. Their age at the time of their injury ranged from 16 to 44 years of age. Time since being injured ranged from 26 to 50 years. The current age range of those interviewed was from 45 to 81 years. Five people were pre-ACC (March 1974) and seven people were under ACC with there being five paraplegics and seven tetraplegics. At the time of injury four people were married. At the time of the interview six people were either married or had a partner.

Results

Theme 1: The Initial Impact of the Injury

1. Whether the person was young or old, male or female, ACC or pre-ACC the impact of suddenly becoming paralysed with the spinal cord injury was sudden, traumatic and dramatic.
2. A major consequence for all those interviewed was the initial impact of coming to terms with urinary and bowel incontinence. For Pre-ACC interviewees the challenges of urinary incontinence were considerable due to the lack of technology that was available and limited medical knowledge and possible options that were available. As a result, many of them are now dealing with complications associated with medical decisions that were made during the 1950s and 1960s.
3. The majority of people initially experienced problems after they left hospital as they began their living with their spinal cord injury in the community. Those people who were pre-ACC had no access to funds to alter their homes, purchase wheelchairs or any other rehabilitation equipment, e.g. car hand controls. They had to purchase such equipment or undertake alterations themselves or community fundraise. It was not until 1972 that the state started to contribute to paying for a person's wheelchair.

Theme 2: Issues Associated With Having a SCI a Long Time

1. The majority of respondents perceived their health to have been relatively good with many commenting on having long episodes of good health interrupted by periodic episodes of ill-health. A general observation would be of the 12 spinal cord injured people interviewed the five paraplegics have tended to have fewer health issues than the seven tetraplegics.
2. Pre ACC interviewees (before 1974) made more specific comments about the public's negative attitudes and lack of understanding when seeing a person in a wheelchair.
3. Like those in the general population, people married, others are still married to their pre-injury partners; other marriages had broken down, and some people had been through a variety of relationships.
4. Many interviewees talked about the lack of access to a regular health reassessment at the Burwood Spinal Injuries Unit. In the past people were used to having a routine call up every couple of years from the Unit for a complete reassessment.
5. Some people had traumatic experiences in hospital due to the treating health professional not having enough experience or knowledge about spinal cord injury.
6. Some interviewees had a lack of access to health services because they lacked the knowledge to follow it through. This indicates a need for education.

7. At the time of the interview, of the 12 interviewees, two were on superannuation, one on a disability allowance, three on ACC's Earnings Related Compensation, and six either worked full-time (4) or part-time (2). Of the three people on ACC earnings related compensation, two had not really worked since their injury and the third person worked part-time until his health deteriorated to the point where the employer would no longer keep him on.
8. Those who commented on their psychological well-being generally felt they had coped well over the years. It was obvious to the interviewer that all the people interviewed were real survivors and the clear majority had a very positive attitude towards life.
9. ACC came into existence 34 years ago on the 1 April 1974. Of the seven people (mean time injured = 29.43 years) under ACC, their opinions were mixed. Some felt they had a terrible relationship with ACC, many felt it depended very much on the attitude of an individual case manager at any particular point in time, and others found that overall the relationship with ACC had been positive.
10. The five people who had their injuries before ACC came into existence have their care paid for by the Ministry of Health and social support by the Department of Social Welfare. Their mean time injured was 42.4 years. Each person had their own personal story about how they survived with little funding and support. The researcher felt very humbled by their individual stories of survival.

Theme 3: Specific Issues Associated With Getting Older

1. All those interviewed recognized that they were starting to experience a wide range of physical issues associated with getting older. Examples included problems with shoulders and neck, increased pain, decreased movement and strength, deterioration in bladder function with an increasing number of bladder infections, kidney stone problems, bowel problems, in some instances resulting in the need for a colostomy, brittle bones, arthritis decreased respiratory function resulting in more chest infections, complications from the original injury being unstable, decreased mobility, resulting in transfers being more difficult, and switching from a manual wheelchair to electric wheelchair.
2. A number of those interviewed talked about the need to adjust as they found things more difficult, such as stopping driving, playing sport, and using different equipment and technology.
3. Those who were older, especially those over 65, talked about how the body did not recover as quickly as it used to and that they had to be much more careful.
4. Some interviewees talked about how they had decided personally to take more control of their health especially in regard to medication, even when this was against medical advice.
5. The issue of a person's partner also becoming older and physically having complications is a reality for some people. In such cases these people are reassessing how they do things or are cared for.
6. With people physically finding things generally harder they have found it harder to maintain friendships or it is more of an effort to do so.
7. The three people that commented on employment issues as they get older all mentioned that they wished to reduce their hours of employment. Two people were physically finding it much more difficult to maintain full employment and in one case the person had reduced his work to three days a week.

8. Those who talked about psychological well-being as they grew older commented on how they had learnt patience and the need to have a positive outlook on life.
9. It was commented that when you are struggling to get an answer from ACC or are in disagreement with ACC, this can cause unnecessary stress.
10. One person interviewed who was a high level tetraplegic with little family support and was pre-ACC (1974) felt there had been little option but to accept institutionalised care. This is the situation 43 years later.
11. There are major funding differences between those people who are under ACC and the Ministry of Health, in regards to the type of support services provided and what equipment can be purchased and paid for. Those under the Ministry of Health are severely disadvantaged compared to those under ACC funding.
12. One person considered that the spinal specialists were learning as they go in regard to medically treating the ageing spinal cord injured person.
13. Three other people commented that they felt that the Burwood Spinal Injuries Unit had let them down since they had stopped doing regular reassessments. It now appears to be reactive medical treatment rather than preventative medicine i.e. in identifying problems before they become a major issue.
14. Three individuals who had their partners/spouses undertaking their cares were starting to recognize that their partners/spouses were starting to have physical problems due their own ageing, which would limit their ability to continue in the caring role. These individuals were recognizing that they needed to look at other options.
15. One person who has had the same carers for many years commented on how beneficial it was having people that knew him well, and also the importance of having stability in his life.

Theme 4: Has Life With Your Injury Turned Out The Way You Thought It Might?

1. Two interviewees commented that they never thought very far ahead.
2. Others did not think ahead initially, but over time have changed not only because they are in a wheelchair but also they have grown older and have more responsibilities i.e. families.
3. One person believed that his life had turned out mostly as it would have if he had not had the injury but then adds he is also amazed at what he has achieved regardless of his disability.
4. Two people specifically suggested that their lives had turned out better than what they had expected.
5. Three people commented about being surprised how life had turned out for them.
6. One pre-ACC person commented that his retirement had not turned out the way he had expected due to his poor health and poor financial situation.

Theme 5: The Key Issues Likely To Be Encountered In The Future

1. Those who had concerns about issues associated with physical deterioration tended to be those who had or were experiencing ill-health or increased periods of ill-health.
2. People recognized that they were going to have to deal with the body wearing out, and find it more difficult to cope physically as they became older.
3. It was recognized that life style changes and the need to adjust were going to be necessary.
4. One interviewee talked about possible developments medical treatment.

Theme 6: What Sort Of Things In The Past Could Have Helped?

Those who did comment made a variety of comments on how things in the past could have helped. This included;

1. Improved technology and medical knowledge.
2. Improved communication with ACC, especially with individual case managers and knowing what people were entitled to.
3. Getting a colostomy earlier post injury.
4. For those who were injured before 1974 to have received similar funding as those people who received ACC funding.
5. The feeling of independence that driving and electric wheelchairs had given people.
6. Using carers rather than a person's partner doing their cares.
7. The benefits of massage on keeping joints flexible.

Theme 7: The Impact of Technology and Changes in Medical Knowledge and Treatment

1. Technological advances especially in regards to light weight and electric wheelchairs had greatly improved peoples quality of life and independence.
2. Changes to the building codes in the early 1980s had meant society had become much more inclusive and accessible for those less mobile.
3. Medical knowledge and treatment advances had greatly improved the longevity of spinal cord injured persons lives and their quality of life.
4. This includes the use of operations such as colostomies and supra pubics.

Theme 8: How a Person's Own Experiences and Knowledge Has Helped Them and Others

1. It was acknowledged by many of those interviewed they had learned a considerable amount from "the oldies", people who had spinal cord injuries before them who they had met while playing sport with or being in the Spinal Injuries Unit.
2. People had learned a considerable amount personally over time and that in some cases this had taken years for them to understand their own bodies and how they functioned differently due to the spinal cord injury.
3. Because those interviewed had lived with their spinal cord injury a very long time many had helped others understand and learn about how to adapt with their disability or acknowledged that they had served as role models for others.

Theme 9: Impact of a Person's Cultural Background

1. Most people felt that their cultural background had had no significant impact on how they ha dealt with their injury.
2. Many related the question to be significant to them in regard to how important the support of their family and friends had been.

Appendix 4 Multi-regional ethics Committee application MEC/09/06/061 approval letter

**Multi-region Ethics Committee**

Ministry of Health
Level 2, 1-3 The Terrace
PO Box 5013
Wellington
Phone (04) 470 0655
(04) 470 0646
Fax (04) 496 2191

Email: multiregion_ethicscommittee@moh.govt.nz

18 September 2009

Richard Peter Smail
Department of Public Health and General Practice
University of Otago
P O Box 4345
Christchurch

Dear Richard

The Implications of Ageing with a Physical Disability

Lead Investigator: Richard Peter Smail

Approved sites: NZ Spinal Trust Christchurch, Canterbury DHB, Association of Spinal Concern (TASC), Auckland Spinal Rehabilitation Unit, Counties Manukau DHB
MEC/09/06/061

The above study has been given ethical approval by the **Multi-region** Ethics Committee.

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 **September 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 by **18 September 2010**. 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.

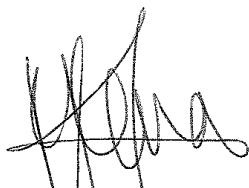
Amendments

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

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

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Rebecca Stewart', written over a horizontal line.

Rebecca Stewart
Multi-region Ethics Committee Administrator
Email: rebecca_stewart@moh.govt.nz

Appendix 5 Questionnaire

Implications of Ageing with a Spinal Cord Injury or Condition
1. INSTRUCTIONS ON HOW TO COMPLETE THIS SURVEY
<p>Please mark the appropriate box with your response. All the information you give is in confidence and will be only used for the purpose of this study. There are no right or wrong answers; we want the response that is best for you. If you require assistance to complete the questionnaire please ask a family member or whānau to assist you, or alternatively a carer. Do not linger too long over each question; usually your first response is the best. The questionnaire will take approximately 30 to 40 minutes to complete.</p> <p>If you need help to answer any questions please contact Richard Smaill either by telephone or via e-mail.</p> <p>Telephone: 0274 356 711[I will ring you back to avoid cost to yourself]</p> <p>Email: rsmail@xtra.co.nz</p> <p>Thank you for taking time to complete the survey</p> <p>1. Example: What is your main form of mobility? (If you use a combination please tick the boxes that best apply to you)</p> <p><input type="checkbox"/> Electric wheelchair</p> <p><input type="checkbox"/> Manual wheelchair</p> <p><input type="checkbox"/> Walking with the use of aid(e.g. crutches)</p> <p><input type="checkbox"/> Walking</p>

Implications of Ageing with a Spinal Cord Injury or Condition

2. BACKGROUND INFORMATION

First we would like to ask you for some general background information. Many of the questions asked are about education, marital status, housing and income derived from the New Zealand census. We need this information to find out how people with a spinal cord injury or condition compared with the whole New Zealand population. Please tick the answer that you believe gives an accurate indication of your CURRENT situation, or write details in the spaces provided.

1. When were you born?

Date born DD MM YYYY
 / /

2. Are you?

- ☐ Female
☐ Male

3. Which one of these statements best describes your current marital status?

(If you have been married more than once, answer for your most recent marriage)

- ☐ I am married
☐ I am in a civil union/de facto/partnered relationship
☐ I am permanently separated from my husband/wife or partner
☐ I am a widow or widower
☐ I have never been married

4. Which ethnic group do you belong to?

(Please tick all the boxes and apply to you)

- ☐ Pakeha/New Zealander of European descent
☐ Māori
☐ Samoan
☐ Cook Island Māori
☐ Tongan
☐ Niuean
☐ Chinese
☐ Indian

Other (please specify)

Implications of Ageing with a Spinal Cord Injury or Condition

5. Which term best describes your spinal cord injury or condition?

(Please indicate the term that best applies to you)

☐ Tetraplegic

☐ Paraplegic

☐ Walking

Other (please specify)

6. At what neurological level did you sustain your injury or condition (E.g. C5, T12 incomplete etc)?

7. What is your main form of mobility?

(If you use a combination please tick those that best apply to you)

☐ Electric wheelchair

☐ Manual wheelchair

☐ Walking with the use of an aid (e.g. walking stick, crutches)

☐ Walking

Other (please specify)

8. How did you have your injury or incur your condition?

(e.g. motor vehicle accident, rugby accident, tumour etc)

9. What year did you have your injury or incur your condition?

Date DD / MM / YYYY

10. Approximately how old were you at the time?

Age

Implications of Ageing with a Spinal Cord Injury or Condition

11. If you receive financial support (e.g. for care, equipment etc) which organisation provides that funding?

(Tick more than one item if appropriate)

- ☐ Ministry of Health (MoH)
- ☐ Accident Compensation Corporation (ACC)
- ☐ District Health Board (DHB)
- ☐ Ministry of Social Development
- ☐ Health Insurance

Other (please specify)

12. If you receive home help and/or attendant care support who are the main provider(s) of that support?

(Tick more than one item of appropriate)

	Home Help	Attendant Care
Nursing agency	<input type="checkbox"/>	<input type="checkbox"/>
Carers organised by myself, family member or whānau	<input type="checkbox"/>	<input type="checkbox"/>
Carers organised by another organisation/person	<input type="checkbox"/>	<input type="checkbox"/>
Spouse or partner	<input type="checkbox"/>	<input type="checkbox"/>
Family member or whānau	<input type="checkbox"/>	<input type="checkbox"/>
Flatmate(s)	<input type="checkbox"/>	<input type="checkbox"/>

Other (please specify)

13. Not counting yourself, please give the total number of other people/whānau that live in the same household as you?

Total number of other people/whānau

14. How many people/whānau not counting yourself, are dependent on you for their financial support?

Total number of other people/whānau

Implications of Ageing with a Spinal Cord Injury or Condition

15. Mark as many spaces as you need to show all the people/whānau who live in the same household as you

- ☐ My husband or wife, partner, de facto, boyfriend or girlfriend
- ☐ My son(s) and/or daughter(s)
- ☐ My mother and/or father
- ☐ My sister(s) and/or brother(s)
- ☐ My flatmate(s)
- ☐ None of the above-I live alone

Other (please specify)

16. If you indicated above that you live with some of your children, please indicate below how many children live in the same house as you and their ages.

Number of children aged 16 or under

Number of children aged 17 or over

17. Which of the following best describes the area where you live? (Please tick one box)

- ☐ Main Urban Area [A city or town with a population of about 30,000 or more]
- ☐ Secondary Urban Area [A town or city with a population of between about 10,000 and 29,999]
- ☐ Minor Urban Area [A town with a population of between 1,000 and 10,000]
- ☐ Rural Area [A town with a population of between 300 and 1,000]
- ☐ Rural Area [Outside a town or city boundaries]

Implications of Ageing with a Spinal Cord Injury or Condition**18. What is your HIGHEST secondary school qualification?****(Please tick one box)**

- ☐ No school qualifications
- ☐ NZ School Certificate in one or more subjects
- ☐ NZ 6th Form Certificate in one or more subjects
- ☐ NZ Higher School Certificate or Higher Leaving Certificate
- ☐ NZ University Entrance
- ☐ NZ A or B Bursary or University Scholarship
- ☐ Overseas secondary school qualification

Other (please specify)

19. Apart from secondary school qualifications, do you have other qualifications? (Please don't count incomplete qualifications or qualifications that take less than three months of full-time study to get)☐ No

Yes (please state your highest qualification)

Implications of Ageing with a Spinal Cord Injury or Condition

20. In the following table:

- Please tick in the first column, THE situation that best describes your CURRENT situation.

- Please tick in the second column, the situation which you would PREFER to be in.

(Tick the box in the same row if you are currently in the preferred situation)

	Your current situation	Your preferred situation
Full-time paid employment, including self-employment	<input type="checkbox"/>	<input type="checkbox"/>
Part-time paid work, including self-employment	<input type="checkbox"/>	<input type="checkbox"/>
Retired, no paid work	<input type="checkbox"/>	<input type="checkbox"/>
Full-time homemaker	<input type="checkbox"/>	<input type="checkbox"/>
Full-time student	<input type="checkbox"/>	<input type="checkbox"/>
Part-time student	<input type="checkbox"/>	<input type="checkbox"/>
Unemployed and seeking work	<input type="checkbox"/>	<input type="checkbox"/>
Sickness benefit	<input type="checkbox"/>	<input type="checkbox"/>
Invalid's benefit	<input type="checkbox"/>	<input type="checkbox"/>
ACC	<input type="checkbox"/>	<input type="checkbox"/>

Not in the workforce - other (please specify below)

21. If in paid employment (including self employment) what is your occupation in your main job?

(Try to be as specific as you can. e.g. Primary School Teacher, Clothing Machinists, Motel Manager, Secretary)

If you are NOT currently in paid employment don't answer and go to question 23.

22. Do you work full-time or part-time?

☐ Full-time

☐ Part-time

23. How many hours (to the nearest hour) do you usually work each week?

In your main job?

In any other jobs (if applicable)?

Implications of Ageing with a Spinal Cord Injury or Condition

24. Is your spouse/partner in paid employment?

(Please tick one box)

- ☐ Full-time paid employment, including self employment
- ☐ Part-time paid work, including self employment
- ☐ Retired, no paid work
- ☐ Full-time homemaker
- ☐ Full-time student
- ☐ Unemployed and seeking work
- ☐ Not applicable (no spouse/partner)

Other (please specify)

25. Tick as many boxes as you need to show all the ways you receive income in the 12 months ending today.

(Please DON'T count loans because they are not income)

- ☐ Wages, salary, commissions, bonuses etc, paid by my employer
- ☐ Self-employment, or business I own and work in
- ☐ Interest, dividends, rent, other investments
- ☐ Regular payments from ACC
- ☐ Regular payments from private work accident insurer
- ☐ New Zealand superannuation or veterans pension
- ☐ Other superannuation, pensions, annuities (other than NZ superannuation, veterans pension or war pension)
- ☐ Unemployment benefit
- ☐ Domestic purposes benefit
- ☐ Invalids benefit
- ☐ Student allowance
- ☐ Other government benefits, income support payments, or war pensions
- ☐ Other sources of income, counting support payments from people who do not live in my household
- ☐ No source of income during that time

Implications of Ageing with a Spinal Cord Injury or Condition

26. What would be the total income that you personally received before tax the last 12 months?

(Please tick one box)

- ☐ Under \$20,000
- ☐ Between \$20,001 to \$30,000
- ☐ Between \$30,001 to \$40,000
- ☐ Between \$40,001 to \$50,000
- ☐ Between \$50,001 to \$60,000
- ☐ Between \$60,001 to \$70,000
- ☐ Between \$70,001 to \$80,000
- ☐ Between \$80,001 to \$90,000
- ☐ Between \$90,001 to \$100,000
- ☐ Over \$100,001

27. What would be the combined income that ALL OTHER MEMBERS of your household received in the last 12 months (exclude your own income)?

(Please tick one box)

- ☐ Under \$20,000
- ☐ Between \$20,001 to \$30,000
- ☐ Between \$30,001 to \$40,000
- ☐ Between \$40,001 to \$50,000
- ☐ Between \$50,001 to \$60,000
- ☐ Between \$60,001 to \$70,000
- ☐ Between \$70,001 to \$80,000
- ☐ Between \$80,001 to \$90,000
- ☐ Between \$90,001 to \$100,000
- ☐ Over \$100,001

Implications of Ageing with a Spinal Cord Injury or Condition

28. Apart from any contribution to New Zealand superannuation through your taxes, are you a current or part-contributor to any of the following superannuation schemes?

(Please tick one box)

- ☐ Kiwi Saver
- ☐ Other employment retirement schemes
- ☐ Other superannuation schemes

29. For the following questions, please indicate whether or not you have (or have access to) the item by ticking ONE of the boxes.

1. Tick the first box if you have the item or have access to it

2. Tick the second box if you don't have the item because you don't want it

3. Tick the third box if you don't have the item because of its cost

4. Tick the fourth box if you don't have the item because of some other reason

	Yes I have it	No because I don't want it	No because of the cost	No for some other reason
Telephone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Washing machine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Heating available in all main rooms	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A good pair of shoes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
A best outfit for special occasions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal computer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Home contents insurance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enough room for guests to stay the night	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30. For the following questions, please indicate whether or not you do the activity by ticking ONE of the boxes.

	Yes I do	No because I don't want to	No because of the cost	No for some other reason
Give presents to family, whānau or friends on birthdays, Christmas, or other special occasions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Visit the hairdresser at least once every three months	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have holidays away from home every year	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have a holiday overseas at least every three years	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have a night out at least once a month	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have family or friends over for a meal at least once a month	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following questions are about your material standard of living - things that money can buy (this does not include your health or capacity to enjoy life). Tick the questions that these apply to you.

Implications of Ageing with a Spinal Cord Injury or Condition**31. Generally, how would you rate your material standard of living?**

- ☐ High
- ☐ Fairly high
- ☐ Medium
- ☐ Fairly low
- ☐ Low

32. Generally, how satisfied are you with your current material standard of living?

- ☐ Very satisfied
- ☐ Satisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Dissatisfied
- ☐ Very dissatisfied

33. How well does your total income meet your everyday needs for such things as accommodation, food, clothing and other necessities?

- ☐ My income is not enough
- ☐ My income is just enough
- ☐ My income is enough
- ☐ My income is more than enough

Implications of Ageing with a Spinal Cord Injury or Condition

3. HEALTH & DISABILITY

We would like to ask you some questions about your health and disability. This information will help us understand how you feel and how well you are able to do your usual activities. For each of the following questions, please tick the box that best describes your answer.

1. In general, would you say your health is:

(Please tick one box)

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor

2. Compared to ONE YEAR AGO, how would you rate your health in general NOW?

(Please tick one box)

- ☐ Much better now than one year ago
- ☐ Somewhat better now than one year ago
- ☐ About the same as one year ago
- ☐ Somewhat worse now than one year ago
- ☐ Much worse than one year ago

3. The following questions are about activities you might do during a typical day. Does your HEALTH AND/OR DISABILITY NOW LIMIT YOU in these activities? If so, how much?

(Please tick one box on each line)

	Yes, limited a lot	Yes, limited a little	Not limited at all
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lifting or carrying groceries	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Climbing several flights of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Climbing one flight of stairs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bending, kneeling, or stooping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking more than 1 km	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking several blocks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Walking one block	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bathing or dressing yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Implications of Ageing with a Spinal Cord Injury or Condition

4. During the PAST 4 WEEKS, how much of the time have you had any of the following problems with your work OR other regular daily activities AS A RESULT OF YOUR PHYSICAL HEALTH?

(Please tick one box on each line)

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Cut down on the amount of time you spend on work or other activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accomplished less than you would like	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Were limited in that kind of work or other activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Had difficulty performing the work or other activities (for example, it took extra effort)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

5. During the PAST 4 WEEKS, how much of the time have you had any of the following problems with your work OR other regular daily activities AS A RESULT OF ANY EMOTIONAL PROBLEMS? (Such as feeling depressed or anxious)

(Please tick one box of each line)

	All of the time	Most of the time	Some of the time	A little of that time	None of the time
Cut down on the amount of time spent on work or other activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accomplished less than you would like	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Were limited in the kind of work or other activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Had difficulty performing the work or other activities (for example, it took the extra effort)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. During the PAST 4 WEEKS, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

(Please tick one box)

- ☐ Not at all
☐ Slightly
☐ Moderately
☐ Quite a bit
☐ Extremely

Implications of Ageing with a Spinal Cord Injury or Condition

7. How much **BODILY** pain have you had during the **PAST 4 WEEKS**?

(Please tick one box)

- ☐ None
☐ Very mild
☐ Mild
☐ Moderate
☐ Severe
☐ Very severe

8. During the **PAST 4 WEEKS**, how much did **PAIN** interfere with your normal work (including both work outside the home and house work)?

(Please tick one box)

- ☐ Not at all
☐ Slightly
☐ Moderately
☐ Quite a bit
☐ Extremely

9. These questions are about how you feel and how things have been with you **DURING THE PAST 4 WEEKS**. For each question, please give the **ONE** answer that is closest to the way you have been feeling. How much of the time during the **PAST 4 WEEKS**.

(Please tick one box on each line)

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Did you feel full of life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been very nervous?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt so down in the dumps that nothing could cheer you up?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt calm and peaceful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have a lot of energy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you felt downhearted and blue?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel worn out?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Have you been happy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you feel tired?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Implications of Ageing with a Spinal Cord Injury or Condition

10. During the PAST 4 WEEKS, how much of the time has your PHYSICAL HEALTH OR EMOTIONAL PROBLEMS interfered with your social activities (like visiting with friends, relatives etc)

(Please tick one box)

- ☐ All of the time
- ☐ Most of the time
- ☐ Some of the time
- ☐ A little of the time
- ☐ None of the time

11. How TRUE or FALSE is each of the following statements for you?

(Please tick one box on each line)

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
I seem to get sick a little easier than other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am as healthy as anybody I know	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I expect my health to get worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My health is excellent	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Implications of Ageing with a Spinal Cord Injury or Condition

12. The following questions focus on HEALTH PROBLEMS you may have. Please tick the box corresponding to the word 'Yes' or 'No' to indicate if a doctor, nurse or other healthcare worker has told you that you have any of the following health problems. (Please do not skip any questions)

	Yes	No
Skin cancer?	<input type="radio"/>	<input type="radio"/>
Other forms of cancer?	<input type="radio"/>	<input type="radio"/>
Diabetes?	<input type="radio"/>	<input type="radio"/>
Epilepsy?	<input type="radio"/>	<input type="radio"/>
High blood pressure or hypertension?	<input type="radio"/>	<input type="radio"/>
Heart trouble (e.g. angina or myocardial infarction)?	<input type="radio"/>	<input type="radio"/>
Asthma?	<input type="radio"/>	<input type="radio"/>
Other respiratory conditions (e.g. bronchitis)?	<input type="radio"/>	<input type="radio"/>
Stomach ulcer or duodenal ulcer?	<input type="radio"/>	<input type="radio"/>
Chronic liver trouble (e.g. cirrhosis)?	<input type="radio"/>	<input type="radio"/>
Bowel disorders (e.g. colitis or polyps)?	<input type="radio"/>	<input type="radio"/>
Hernia or rupture?	<input type="radio"/>	<input type="radio"/>
Chronic kidney or urinary tract conditions?	<input type="radio"/>	<input type="radio"/>
Chronic skin conditions (e.g. dermatitis or psoriasis)?	<input type="radio"/>	<input type="radio"/>
Arthritis or rheumatism?	<input type="radio"/>	<input type="radio"/>
Hepatitis?	<input type="radio"/>	<input type="radio"/>
Sight impairment (that cannot be corrected by glasses)?	<input type="radio"/>	<input type="radio"/>
Hearing impairment?	<input type="radio"/>	<input type="radio"/>
Stroke?	<input type="radio"/>	<input type="radio"/>

The following questions concern your alcohol consumption. For each question, please tick the answer that is correct for you.

13. How often do you have a drink containing alcohol?

(Please tick one box)

- ☐ Never
- ☐ Monthly or less
- ☐ Two to four times a month
- ☐ Two to three times a week
- ☐ Four or more times a week

If you ticked 'NEVER' to the question above please answer the question below otherwise go straight to question 15.

Implications of Ageing with a Spinal Cord Injury or Condition**14. Have you ever drunk alcohol in the past?****(Once you have answered this question, please go straight to Question 17)**

- ☐ Yes
- ☐ No

15. How many drinks containing alcohol do you have on a typical day when drinking?**(Please tick one box)**

- ☐ 1 or 2
- ☐ 3 or 4
- ☐ 5 or 6
- ☐ 7 to 9
- ☐ 10 or more

16. How often do you have six or more drinks on one occasion?**(Please tick one box)**

- ☐ Never
- ☐ Less than monthly
- ☐ Monthly
- ☐ Weekly
- ☐ Daily or almost daily

The following questions concerning your use of health services (such as doctors or hospitals). For each question, please tick the answer that is correct you.

17. In the last 12 months, have you seen a doctor or been visited by a doctor ABOUT YOUR OWN HEALTH? By 'Doctor' we mean any GP or family doctor, but not a specialist.**(Please tick one box)**

- ☐ Yes
- ☐ No (Tick and go down to Question 19)
- ☐ Don't know (Tick and go down to Question 19)

Implications of Ageing with a Spinal Cord Injury or Condition**18. How many times?****(Please tick one box)**

- ☐ 1 time
- ☐ 2 times
- ☐ 3 to 5 times
- ☐ 6 to 11 times
- ☐ 12 times or more
- ☐ Don't know

19. In the last 12 months, have you yourself used a service at, or been admitted to, a hospital (either public or private)?**(Please tick one box)**

- ☐ Yes
- ☐ No (Tick and go down to Question 21)
- ☐ Don't know (Tick and go down to Question 21)

20. In the past 12 months, how many times were you admitted for one night or longer?**(Please tick one box)**

- ☐ Never admitted overnight
- ☐ 1 to 2 times
- ☐ 3 to 4 times
- ☐ 5 or more times

21. In the last 12 months, how many times did you go to the hospital emergency department as a patient?**(Please tick one box)**

- ☐ never
- ☐ 1 to 2 times
- ☐ 3 to 4 times
- ☐ 5 or more times

Implications of Ageing with a Spinal Cord Injury or Condition

22. In the last 12 months, have you seen any of the following people for healthcare or advice for yourself?

(Tick all that apply)

- ☐ GP's practice nurse, without seeing the doctor
- ☐ district, public health or other nurse
- ☐ chemist or pharmacist, for health advice or medication only
- ☐ physiotherapist
- ☐ dentist or dental nurse
- ☐ optician or optometrist
- ☐ chiropractor or osteopath
- ☐ podiatrist or chiropodist
- ☐ alternative therapist such as a naturopath, homoeopath, iridologist or acupuncturist
- ☐ psychologist or counsellor
- ☐ occupational or speech therapist
- ☐ traditional healer such as a tohunga, rongoa, Maori specialist or fofo
- ☐ Māori health worker, Pacific Island health worker
- ☐ other specialist medical practitioner (e.g. urologists, neurologist, oncologist, spinal specialist)

23. Would you currently consider yourself a regular smoker?

(Please tick one box)

- ☐ Yes (Tick and go to question 24)
- ☐ No (Tick and go to question 25)

24. IF YOU CONSIDER YOURSELF A REGULAR SMOKER: How many do you think you would smoke on an average day?

(Please tick one box)

- ☐ 1 to 10 a day
- ☐ 11 to 20 a day
- ☐ 21 to 30 a day
- ☐ 31 or more a day

Implications of Ageing with a Spinal Cord Injury or Condition

25. IF YOU DO NOT CONSIDER YOURSELF A REGULAR SMOKER: Have you, at any stage of your life, ever been a regular smoker?

(Please tick one box)

☐ Yes

☐ No

Implications of Ageing with a Spinal Cord Injury or Condition

4. PHYSICAL ACTIVITY

The following questions concern the kinds of physical activities that people do as a part of their everyday lives. Please answer each question even if you do not consider yourself to be an active person. Please think about the activities you do at work, as part of your house and garden work, to get from place to place or in your spare time for recreation, exercise or sport.

1. If you add up all the times you spent in each activity in the last LAST 7 DAYS, how much time did you spend ALTOGETHER doing each type of activity?

(Please put the TOTAL NUMBER OF HOURS AND MINUTES over the last 7 days. If you did not do an activity, please write '0' in the box)

PUSHING WHEELCHAIR OR BRISKLY WALKING (at a pace where you are breathing harder than normal, BUT ONLY A LITTLE HARDER. E.g. for recreation or exercise, or to get from place to place)

MODERATE PHYSICAL ACTIVITY (which makes you breathe harder than normal, BUT ONLY MODERATELY HARDER. E.g. carrying light loads, gardening, pushing wheelchair, bicycling at regular pace, recreational swimming)

VIGOROUS PHYSICAL ACTIVITY (that makes you breathe a lot harder than normal or huff and puff, E.g. heavy lifting, pushing wheelchair hard, fast biking, aerobics, running)

2. Thinking about all your physical activities on how many of the LAST 7 DAYS were you active? ('Active' means doing 15 minutes or more of vigorous activity, OR 30 minutes of more moderate activity or brisk walking)

(Please tick one box)

- ☐ 0 days
 ☐ 1 day
 ☐ 2 days
 ☐ 3 days
 ☐ 4 days
 ☐ 5 days
 ☐ 6 days
 ☐ 7 days

3. Please indicate which of the following describes your physical activity over the PAST 6 MONTHS. ('Regular physical activity' means doing 15 minutes or more vigorous activity, OR 30 minutes or more moderate activity of brisk walking each day for five or more days a week)

(Please tick one box)

- ☐ I am NOT regularly physically active and DO NOT intend to be so in the next six months
☐ I am NOT regularly physically active but am thinking about starting in the next six months
☐ I do some physical activity but NOT enough to be described as regular physical activity
☐ I am regularly physically active but only began in the last six months
☐ I am regularly physically active and have been so for longer than six months

Implications of Ageing with a Spinal Cord Injury or Condition

5. SUPPORT

The following section of the survey focuses on your social networks, your beliefs about yourself and your beliefs about your family and whānau.

1. I contribute my time and/or labour to volunteer activities:

(Please tick one box)

- ☐ Very often
☐ Often
☐ Sometimes
☐ Rarely
☐ Never

2. How far away, in distance, does your nearest:

(Please tick one box on each line)

	same house/within 1 km	1 to 5 km	6 to 15 km	16 to 50 km	50+ km	NA/none living
Relative/whānau live (not including your spouse/child/siblings)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child live?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brother or sister live?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3. How often do you speak to or do something with:

(Please tick one box on each line)

	Daily	2 to 3 times a week	At least weekly	At least monthly	Less often	Never/I have none
Any of your children or other relatives/whānau?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Any friends in your community/neighbourhood?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Any of your neighbours?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

4. Please answer the following questions about your contact with family/whānau and friends.

(Please tick one box on each line)

	Yes	No
Do you feel you have regular contact with your family/whānau?	<input type="radio"/>	<input type="radio"/>
Do you feel you have regular contact with your friends?	<input type="radio"/>	<input type="radio"/>
Do you regularly participate in family/whānau activities?	<input type="radio"/>	<input type="radio"/>
Do you have family/whānau or friends over for a meal at least once a month?	<input type="radio"/>	<input type="radio"/>

Implications of Ageing with a Spinal Cord Injury or Condition

5. To what extent do you agree that each statement describes your current relationships with other people?

(Please tick one box on each line)

	Strongly disagree	Disagree	Agree	Strongly agree
There are people I can depend on to help me if I really need it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel that I DO NOT have close personal relationships with other people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is no one I can turn to for guidance in times of stress.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There are people who depend on me for help.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There are people who enjoy the same social activities I do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other people do not view me as competent.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel personally responsible for the well-being of another person.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel part of a group of people who share my attitudes and beliefs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I do not think other people respect my skills and abilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If something went wrong, no one would come to my assistance.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have close relationships that provide me with a sense of emotional security and well-being.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is someone I could talk to about important decisions in my life.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have relationships where my competence and skills are recognised.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is no one who shares my interests and concerns.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is no one who really relies on me for their well-being.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is a trustworthy person I could turn to for advice if I were having problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel a strong emotional bond with another person.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is no one I can depend on for aid if I really need it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is no one I feel comfortable talking about problems with.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There are people who admire my talents and abilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I lack a feeling of intimacy with another person.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There is no one who likes to do things I do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
There are people I can count on an emergency.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
No one needs me to care for them.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. Do you regularly provide unpaid care for grandchildren or other people's children?

(Please tick one box)

- ☐ Yes, daily
☐ Yes, weekly
☐ Yes, occasionally
☐ No, never

Implications of Ageing with a Spinal Cord Injury or Condition

7. Do you regularly provide care or assistance (e.g. personal care, transport) to any of the following people because of their long term illness, disability or frailty?

(Please tick one box on each line)

	Yes	No
Someone who lives with you	<input type="radio"/>	<input type="radio"/>
Someone who lives elsewhere	<input type="radio"/>	<input type="radio"/>

If you answered 'YES' to EITHER of the above go on to Question 8.

If you answered 'NO' to BOTH of the above, go straight to Question 11.

8. How many people with long-term illness, disability or frailty do you regularly provide care for?

(Please tick one box)

- ☐ One person
- ☐ Two people
- ☐ More than two people
- ☐ N/A

9. How often in total do you provide this care or assistance?

(Please tick one box)

- ☐ Every day
- ☐ Several times a week
- ☐ Once a week
- ☐ Once every few weeks
- ☐ Less often

10. How much time do you usually spend providing such care or assistance on each occasion?

(Please tick one box)

- ☐ All day and night
- ☐ All day
- ☐ All night
- ☐ Several hours
- ☐ About an hour

Implications of Ageing with a Spinal Cord Injury or Condition

11. Which of the following statements do you agree with most?

(Please tick one box)

- ☐ People can always be trusted
- ☐ People can usually be trusted
- ☐ You usually can't be too careful
- ☐ You almost always can't be too careful
- ☐ Don't know

12. Some people tell us they feel lonely or isolated while others say that they don't. In the last 12 months how often have you felt lonely or isolated?

(Please tick one box)

- ☐ Always
- ☐ Most of the time
- ☐ Sometimes
- ☐ Rarely
- ☐ Never
- ☐ Don't know

13. Do you attend any of the following:

(Please tick one box on each line)

	Yes, regularly	Yes, on occasions	No
Religious meetings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Meetings of any community/neighbourhood or social groups, such as clubs, lectures or anything like that	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

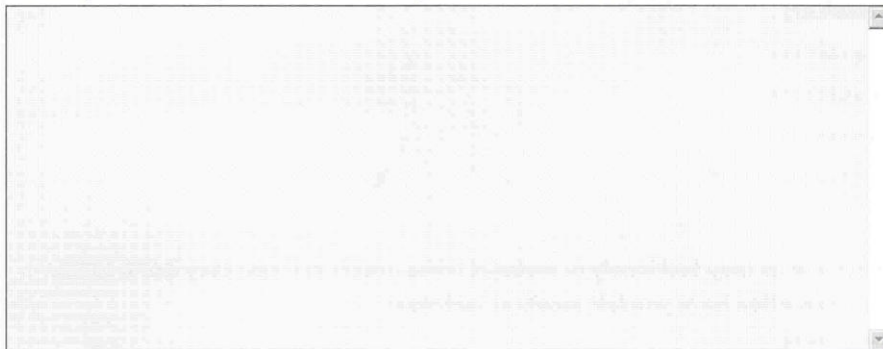
14. Please answer the following questions about how you contact people.

(Please tick one box on each line)

	Yes	No
Do you regularly use a telephone to contact family/whānau, friends or colleagues?	<input type="radio"/>	<input type="radio"/>
Do you regularly use e-mail to contact family/whānau, friends or colleagues?	<input type="radio"/>	<input type="radio"/>
Do you regularly use the Internet (i.e. online chat rooms, purchasing goods or services)	<input type="radio"/>	<input type="radio"/>

Implications of Ageing with a Spinal Cord Injury or Condition

15. Do you have any other comments you would like to make?

A large, empty text box with a light gray background and a thin black border. It contains no text or other content.

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS SURVEY

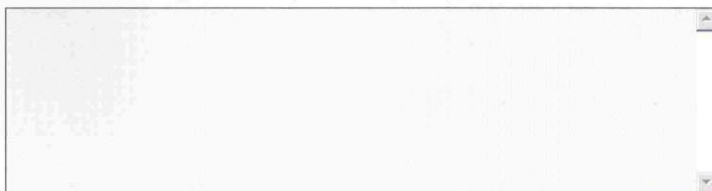
Implications of Ageing with a Spinal Cord Injury or Condition

6. A REQUEST TO TAKE PART IN FUTURE RESEARCH STUDIES

The present study is being done to help us understand the factors that affect people ageing with a spinal cord injury or condition.

We would like to invite you to take part in future research regarding your plans, expectations and experiences in relation to health, and your social life. This would involve completing further surveys in the future. You are under no obligation to take part in future research (it is your choice). If you agree to be contacted in the future please complete your name and contact details below.

1. Please place your name, address, telephone and e-mail details below:



Appendix 6 Multi-regional ethics Committee application MEC/11/01/002 approval letters



Multi-region Ethics Committee
Ministry of Health
No. 1 The Terrace
PO Box 5013
Wellington 6145
Phone (04) 816 2655
(04) 816 2646
Fax (04) 496 2340
Email: multiregion_ethicscommittee@moh.govt.nz

4 May 2011

Dr Richard Peter Smaill
University of Otago - Christchurch School of Medicine
Department of Public Health and General Practice
University of Otago
P O Box 4345
Christchurch

Dear Dr. Smaill:

Re: Ethics ref: **MEC/11/01/002** (please quote in all correspondence)
Study title: The Implication of Ageing with a Spinal Cord Injury or Condition
Investigators: Dr Richard Peter Smaill, Dr Patrick Graham, Dr Sally Keeling, Associate Professor Pauline Barnett

This study was given ethical approval by the Multi-region Ethics Committee on the 27th of April 2011.

Approved Documents

- Amended pages of the National Application Form
- Amended Questionnaire
- Amended Cover Letter to the Participant
- Amended Participant Information Sheet
- Amended Consent Form

This approval is valid until the 31st of April 2016, provided that Annual Progress Reports are submitted (see below).

Access to ACC

For the purposes of section 32 of the Accident Compensation Act 2001, the Committee is satisfied that this study is not being conducted principally for the benefit of the manufacturer or distributor of the medicine or item in respect of which the trial is being carried out. Participants injured as a result of treatment received in this trial will therefore be eligible to be considered for compensation in respect of those injuries under the ACC scheme.

Amendments and Protocol Deviations

All significant amendments to this proposal must receive prior approval from the Committee. Significant amendments include (but are not limited to) changes to:

- the researcher responsible for the conduct of the study at a study site
- the addition of an extra study site
- the design or duration of the study
- the method of recruitment
- information sheets and informed consent procedures.

Significant deviations from the approved protocol must be reported to the Committee as soon as possible.

Annual Progress Reports and Final Reports

The first Annual Progress Report for this study is due to the Committee by the 4th of May 2012. The Annual Report Form that should be used is available at www.ethicscommittees.health.govt.nz. Please note that if you do not provide a progress report by this date, ethical approval may be withdrawn.

A Final Report is also required at the conclusion of the study. The Final Report Form is also available at www.ethicscommittees.health.govt.nz.

Requirements for the Reporting of Serious Adverse Events (SAEs)

For the purposes of the individual reporting of SAEs occurring in this study, the Committee is satisfied that the study's monitoring arrangements are appropriate.

SAEs occurring in this study must be individually reported to the Committee within 7-15 days only where they:

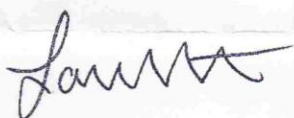
- are *unexpected* because they are not outlined in the investigator's brochure, and
- are not defined study end-points (e.g. death or hospitalisation), and
- occur in patients located in New Zealand, and
- if the study involves blinding, result in a decision to break the study code.

There is no requirement for the individual reporting to ethics committees of SAEs that do not meet all of these criteria. However, if your study is overseen by a data monitoring committee, copies of its letters of recommendation to the Principal Investigator should be forwarded to the Committee as soon as possible.

Please see www.ethicscommittees.health.govt.nz for more information on the reporting of SAEs, and to download the SAE Report Form.

We wish you all the best with your study.

Yours sincerely



Lauren Koste
Administrator
Multi-region Ethics Committee
Email: lauren_koste@moh.govt.nz


Multi-region Ethics Committee,

Ministry of Health
 No. 1 The Terrace
 PO Box 5013
 Wellington 6145
 Phone (04) 816 2403
 (04) 816 2646
 Fax (04) 496 2343

Email: multiregion_ethicscommittee@moh.govt.nz

1 September 2011

Dr Richard Peter Smaill
 University of Otago - Christchurch School of Medicine
 Department of Public Health and General Practice
 University of Otago
 P O Box 4345
 Christchurch

Dear Dr Smaill -

Ethics ref: **MEC/11/01/002** (please quote in all correspondence)
 Study title: The Implication of Ageing with a Spinal Cord Injury or Condition

Thank you for your email dated the 18th August 2011 enclosing documentation relating to the above named study. This documentation has been reviewed and approved by the Chairperson of the Multi-region Ethics Committee under delegated authority.

Approved Documents

- Letter signed and dated 18 August 2011 by Richard Smaill informing the committee that the trial study has been completed by ten respondents. Feedback from these respondents has resulted in amendments to the questionnaire which are listed

Please do not hesitate to contact me should you have any queries.

Yours sincerely

A handwritten signature in dark ink, appearing to read 'L Burlison'.

Laura Jayne Burlison
 Administrator
 Multi-Region Ethics Committee
 Email: Multiregion_ethicscommittee@MOH.govt.nz

Appendix 7 Spinal Network News article in the May 2011 issue

SCI AND AGEING

Richard Smail is a man on a mission! A PhD student at the University of Otago in Christchurch, he is researching ageing with a spinal cord injury/impairment for his doctorate. But, he is doing his work from a wheelchair, and, with an understanding born of a rugby injury sustained when he was 15.

"This is a topic close to my heart. I had a spinal cord injury 36 years ago. I'm getting on a bit now, as are many of my SCI friends, and we are a new group in society. In the old days we all died young, but many of us now living longer and wondering what the future holds," Richard says.

Richard has already interviewed 12 people with spinal cord injuries in Christchurch who have been injured for 25 years or more. They range in age from 45 to 81, and their injuries occurred across all ages, from when they were 16 to 44 years. The interviews generally support the findings from overseas studies that there was significant physical deterioration and complications from the injury itself, but that the group was also affected by the normal ageing processes that affect the wider community, such as heart disease and other chronic diseases. Social, community and cultural issues also mattered to this group.

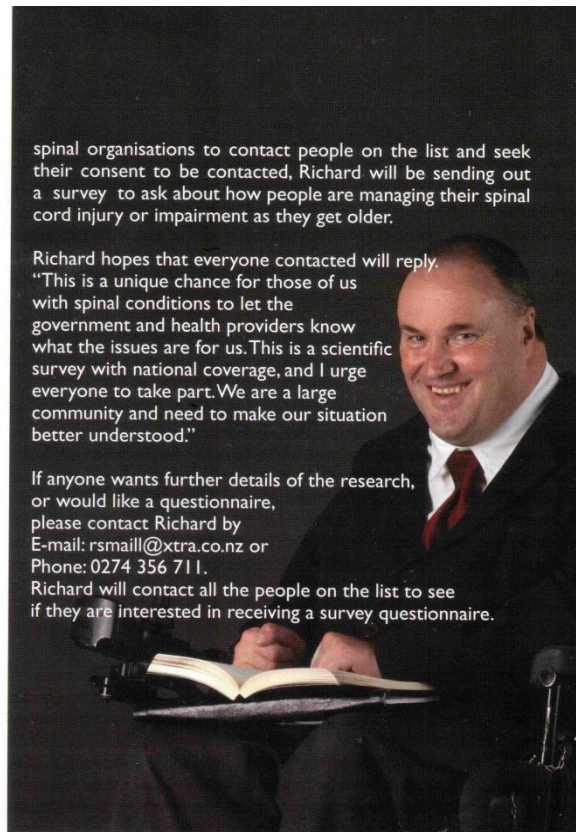
The next step for Richard has been to identify as many people as possible who have had spinal cord injury/impairment for 20 years or longer. With the approval of the Multi-Regional Ethics Committee, and the help of the New Zealand Spinal Trust, Auckland Spinal Rehabilitation Unit and the Burwood Spinal Unit, he has created a list of around 1000 people, many more than anyone thought could be located. Later this year, again with Ethics Committee approval and the help of the

spinal organisations to contact people on the list and seek their consent to be contacted, Richard will be sending out a survey to ask about how people are managing their spinal cord injury or impairment as they get older.

Richard hopes that everyone contacted will reply. "This is a unique chance for those of us with spinal conditions to let the government and health providers know what the issues are for us. This is a scientific survey with national coverage, and I urge everyone to take part. We are a large community and need to make our situation better understood."

If anyone wants further details of the research, or would like a questionnaire, please contact Richard by E-mail: rsmail@xtra.co.nz or Phone: 0274 356 711.

Richard will contact all the people on the list to see if they are interested in receiving a survey questionnaire.



NEW ZEALAND SPINAL TRUST CONTRIBUTORS

Thank you all so very much. Your generosity enables the NZST to continue to offer services and support to people with spinal cord injuries and their families.

Financial Contributors for this quarter

Donations

Pub Charity
Lion foundation
The Freemasons Grand Charity
Simon Gilroy
Deirdre Bartlett
Family of Maurice Wright
Tegal foods



New Zealand Spinal Trust
Te Taratihu Manaaki Tuanui

Dove Electronics
Cyclone computers
Gen-i

Rhett Brown
Digi Web

Christopher Green
Springfree Trampolines
Bunnings Shirley Branch



For Sale

Registered NZ new in 2000, 49,000 km, passenger and driver seat are removable enabling it to be carer driven or self drive, high roof line, CD player/stacker, wide electric ramp & door with remote control, tow bar.

For more details please phone Clem Pedley on (0274) 535654 ⁹

Appendix 8 Letters of introduction from two spinal units



25 July 2011

Dear Prospective Participant

RE: Research Study on the Implications of Ageing with a Spinal Cord Injury or Condition

The Auckland Spinal Rehabilitation Unit, Counties Manukau District Health Board (CMDHB) has been asked to support and assist with a research project being undertaken by Richard Smaill. Richard is a PhD student who is researching the implications of ageing with a spinal cord injury or spinal condition. Richard has been tetraplegic since 1974.


The Auckland Spinal Rehabilitation Unit/CMDHB supports this research project.

To assist Richard we are contacting you and other people who, from our records, had their initial spinal cord injury or spinal condition before January 1990. Every attempt has been made to ensure the accuracy of the contact information obtained from our records. If for some unforeseen reason the contact information is incorrect, we apologize for any inconvenience. The purpose of this letter is to introduce Richard and inquire whether you would be interested in taking part in the research survey. Enclosed with this letter is a detailed information sheet prepared by Richard that explains the research project in detail.

This research study has full Multi-Regional Ethics Committee approval (No: MEC/11/01/002). After reading the information sheet, would you please complete the enclosed form either consenting that you are happy for the Auckland Spinal Rehabilitation Unit to pass on your contact details to Richard, or indicating that you decline to give permission for your contact details to be passed on.

Once you have completed the form please return it to Doreen Yee, Research Study Coordinator, c/o the Auckland Spinal Rehabilitation Unit in the enclosed self addressed postage paid envelope. Thank you for taking the time to read the enclosed information and for your assistance.

Yours sincerely,


Cynthia Bennett, M.D., BSPT, FAAPMR, FAFRM (RACP)
 Rehabilitation Consultant and Clinical Director
 Auckland Spinal Rehabilitation Unit

16 June 2011

Dear

RE: Research Study on the Implications of Ageing with a Spinal Cord Injury or Condition

The Burwood Spinal Unit, Canterbury District Health Board (CDHB) has been asked to support and assist with a research project being undertaken by Richard Smail. Richard is a PhD student who is researching the implications of ageing with a spinal cord injury or condition. Richard has been a tetraplegic himself since 1974.

The Burwood Spinal Unit fully supports this research project as it believes this is an important topic and information gained from the research study has potential to benefit spinal cord injured people. It will assist with gaining important information about the requirements and needs for those ageing with a spinal cord injury or condition.

To assist Richard, we are contacting you and other people who from our records had their initial spinal injury or condition before January 1990. Every attempt has been made to ensure the accuracy of the contact information obtained from our records however if for some unforeseen reason the contact information is incorrect I apologise for any inconvenience. The purpose of this letter is to introduce Richard and enquire whether you would be interested in taking part in the research survey. Enclosed with this letter is a detailed summary information sheet prepared by Richard that explains the research project in detail.

The Research Project has full Multi-Regional Ethics Committee approval (No: MEC/11/01/002). After reading the information sheet, could you please complete the enclosed form either consenting that you are happy for the Burwood Spinal Unit to pass on your contact details to Richard, or indicating that you decline to give permission for your contact details to be passed on to Richard.

Once you have completed the form please return it to Karen Marshall – Research Study Co-ordinator in the enclosed self addressed postage paid envelope. I appreciate you taking the time to read the enclosed information.

Thank you for your assistance.

Yours sincerely



Mr B Singhal, MBBS, FRCS, CCT Rehab Medicine (UK), FAFRM (RACP)
Consultant
Burwood Spinal Unit

Appendix 9 Summary Information sheet and Consent form



15 September 2011

Dear Consenting Respondent,

RE: Research Study on the Implications of Ageing with a Spinal Cord Injury or Condition

Thank you for recently agreeing to participate in the research study into ageing with a spinal cord injury or condition.

You have opted to have the questionnaire sent to you by post to complete. Enclosed with this letter is the questionnaire, which should take approximately 30 to 40 minutes to complete. When you have completed the questionnaire please place in the return addressed envelope and post.

You are free to withdraw from the research study at any time, or to decline to answer any particular question. However, survey participants are urged to complete all the questions if possible.

If you have any queries please refer to the information sheet that you received when you agreed to take part in the study or ring me on my mobile number 0274 356 711 and leave a message. I will return your phone call as soon as possible.

Once again thank you for completing the questionnaire. When the overall results have been analysed and written up I will send you a summary of the key results.

Regards

Richard Smail
PhD Student

This research has the approval of the Multi-regional Ethics Committee No: (MEC/11/01/002)

University of Otago, Christchurch
Department of Public Health & General Practice
PO Box 4345, Christchurch 8140, New Zealand
Public Health Tel +64 3 364 3624 • Fax +64 3 364 3614 • General Practice Tel +64 3 364 3613 • Fax +64 3 364 3637
Email publichealth.uoc@otago.ac.nz • Web www.uoc.otago.ac.nz

Version 4 dated 1.9.11

Summary Information Sheet

Project: Implications of Ageing with a Spinal Cord Injury or Condition
Researcher: Richard Smaill, PhD student
Supervisor: Dr Sally Keeling
Department: Medicine. University of Otago Christchurch

Why investigate people ageing with a spinal cord injury or condition?

In the last 40-50 years a new sub-group has emerged within society, people with moderate to severe disabilities from a spinal cord injury or condition. This has come about due to increased life expectancy and survivorship through improved medical care and knowledge of caring techniques. As people age with spinal cord injury or condition questions arise about how resources can be allocated appropriately and expanding needs met. It is the overall aim of the proposed study to analyse the issues posed by these developments both for policy makers and for those of us who are ageing with a spinal cord injury or condition. It is important that information is collected and policy issues are discussed regarding the issues that people ageing with a spinal cord injury or condition may have.

It is recognised, from both international and NZ evidence that there are:

- (iii) growing pressure on health and disability resources
- (iv) rising expectations based on new technology and human rights.

Given these trends, the issue of ageing with a spinal cord injury or condition has become increasingly important.

What are the specific aims of the study?

To survey as many New Zealand-based people with a spinal cord injury or condition as possible who experienced their initial spinal cord injury/condition before January 1990. The objectives of the study are;

1. To gain insight and learn about the issues and challenges people ageing with a spinal cord injury or condition are having in New Zealand. This information can be compared with the considerable international literature on ageing with a spinal cord injury or condition.
2. Specific reference will be made to establish whether there are differences according to:
 - Whether or not people are supported by the Ministry of Health or ACC.
 - Demographic information such as sex, age, time since injury/condition, and injury/condition characteristics etc.
 - Employment and economic status.
 - Life satisfaction and perceived quality of life.
 - Current environmental conditions/barriers that influence quality of life

What does completing the questionnaire involve?

If you agree to participate in the research study, it is anticipated that the confidential questionnaire will take approximately 30 to 40 minutes to complete. You will complete the questionnaire in one of two ways;

- Via a secure Survey website or
- Being sent a questionnaire; completing it manually and then posting it back to the researcher in a prepaid envelope.

You are free to withdraw from the research study at any time, or to decline to answer any particular question. However, survey participants are urged to complete all questions if possible.

What happens to the information obtained from the questionnaire?

All individual questionnaire information will remain confidential and only be available to the researcher and his immediate supervisor. All written material will be securely stored in a locked cabinet in the Department of Public Health and General Practice in Christchurch. This stored information will be kept up to 10 years, where after it will be physically destroyed.

The information from the questionnaires will be collated on a centralized computer database and where suitable statistical analysis will be undertaken to investigate and identify any significant trends.

This will be done in a way which does not identify individuals. The summarized information will become part of a PhD research project. This may result in a published research paper at a later date. Ensuring confidentiality of individual questionnaires will always be given the highest priority.

Further Information or Queries

Please contact Richard Smaill (mobile 0274 356 711) or his supervisor Dr Sally Keeling, at the Dept of Medicine, University of Otago Christchurch P.O. Box 800 Christchurch. Telephone (03)337-7932.

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent Health and Disability Advocate (New Zealand wide) as follows:

Free Phone: 0800 555 050

Free Fax: 0800 2787 7678 (0800 2 SUPPORT)

Email: advocacy@hdc.org.nz

Website: advocacy.hdc.org.nz

Thank you for your cooperation and participation in this study

This research has the approval of the Multi-regional Ethics Committee (No: MEC/11/01/002)

CONSENT FORM

Project: The Implications of Ageing with a Spinal Cord Injury or Condition
Researcher: Richard Smaill, PhD Student

Instructions

Please read the information below and sign on the back of this page to either consent or decline consent to be contacted regarding this study. Then please enclose this sheet in the self-addressed envelope supplied. Thank you.

For Those Consenting To Completing The Questionnaire

4. I have read the Information Sheet for this study and I understand that I may ask further questions at any time.
5. I understand that I am free to withdraw from the study at any time, or to decline to answer any particular questions in the questionnaire.
6. I agree to provide information to the researcher under the conditions of confidentiality set out on the Information Sheet.
7. I wish to participate in this study under the conditions set out in the Information Sheet.
8. I understand that if I have any queries or concerns at any stage I can contact Richard Smaill (mobile 0274 356 711) or his supervisor Dr Sally Keeling, at the Department of Medicine, University of Otago, Christchurch, P.O. Box 800, Christchurch (telephone (03) 337 7932).

I understand that if I have any queries or concerns regarding my rights as a participant in this study, I may wish to contact an independent Health and Disability Advocate (New Zealand wide) as follows:

Free Phone: 0800 555 050
Free Fax: 0800 2787 7678 (0800 2 SUPPORT)
Email: advocacy@hdc.org.nz
Website: advocacy.hdc.org.nz

I give consent for the Burwood Spinal Unit, Canterbury District Health Board to give my contact details to Richard Smaill PhD student to enable him to send a questionnaire to me.

YES ☐

NO ☐

If you ticked 'YES', giving consent, please tick the box below indicating your preferred option for completing the questionnaire.

☐

Please send me details by email on how to complete the questionnaire on a secure Survey website.

My email is: _____ (please write clearly)

☐

Please send me a questionnaire in the post which I will complete and return in a supplied postage paid envelope. I confirm my address as:

Please complete the information below and place in the self-addressed envelope supplied. Thank you.

Name: _____

Signature: _____

Date: _____

Request for interpreter

English	I wish to have an interpreter	Yes	No
Deaf	I wish to have a NZ sign language interpreter	Yes	No
Māori	E hiahia ana ahau ki tetahi kaiwhaka Māori/kaiwhaka pakeha korero	Ae	Kao
Cook Island Māori	Ka inangaro au i tetahi tangata uri reo	Ae	Kare
Fijian	Au gadreva me dua e vakadewa vosa vei au	Io	Sega
Niuean	Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu	E	Nakai
Sāmoan	Ou te mana'o ia i ai se fa'amatala upu	Ioe	Leai
Tokelaun	Ko au e fofou ki he tino ke fakaliliu te gagana Peletania ki na gagana o na motu o te Pahefika	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea	Io	Ikai

Multi-regional Ethics Committee Approval Number: (MEC/11/01/002)