

School of Physiotherapy and Exercise Science

**Increasing physical activity levels among individuals with spinal cord
injury**

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**This thesis is presented for the Degree of
Doctor of Philosophy
of
Curtin University**

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Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university. To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made.

Signature:

Date:

Statement of Originality

This thesis is presented for the degree of Doctor of Philosophy at Curtin University, Western Australia. Studies were undertaken between February 2011 and November 2014, through the School of Physiotherapy and Exercise Science at Curtin University, in association with the Spinal Cord Injury and Physical Activity program. All material presented in this thesis is original.

The PhD candidate developed this research in association with her supervisors, who were involved in the elaboration of the methods section and editing this thesis. The PhD candidate was responsible for the implementation of the research program, data collection and analysis, as well as writing this thesis.

Abstract

Background

This PhD program formed the basis of three studies completed within the Spinal Cord Injury and Physical Activity in the Community (SCIPA Com) program. SCIPA Com is an original initiative that promoted re-integration of people with spinal cord injury (SCI) into physically active life styles post-discharge from rehabilitation services. The aims of SCIPA Com were to:

- 1) ensure risk management and increase physical activity levels among individuals with SCI within community fitness centres;
- 2) document the effect of physical activity on leisure time physical activity (LTPA) levels, functional goal achievement, self-esteem, and quality of life;
- 3) determine whether a community-based physical activity program reduce barriers and facilitated physical activity among individuals with SCI;
- 4) identify differences between the outcomes of active and inactive individuals with SCI;
- 5) determine long-term LTPA participation following SCIPA Com;
- 6) identify positive personality attributes considered important for LTPA uptake from two different perspectives: exercise professionals and clients with SCI; and
- 7) establish how positive personality attributes influence LTPA levels over time.

Methods

Study 1: In a mixed methods study, community dwelling adults with SCI were assessed via the *Barriers to Physical Activity and Disability Survey* (B-PADS, N=85) and through semi-structured interviews (N=37) carried out on two occasions: before and after participation in the SCIPA Com. Two-tailed significance and chi-square testing at alpha level .05 were performed to detect differences between active and inactive groups.

Study 2: A quasi-experimental translational design was conducted to analyse the outcomes of SCIPA Com. This program included two stages: 1) training exercise professionals via the *Train the Trainers Spinal Cord Injury® (T3-SCI®)*; and 2) implementation of physical activity programs in community fitness centres based on

the clients' physical strengths, personality, and goals. LTPA levels, functional satisfaction, self-esteem and quality of life were assessed among two groups with SCI distinguished by baseline physical activity levels: active (n=27) and inactive (n=37). Linear mixed models were applied to analyse outcomes over time.

Study 3: Two positive personality attribute scales (one for individuals with SCI and another for exercise professional) were developed prior to the commencement of the eight-to-twelve week physical activity program. They were completed by clients with SCI (n=58) and exercise professionals (n=32) following the intervention period. Path analysis was used to identify predictors of physical activity behaviour.

Results

Study 1: B-PADS scores and thematic analysis revealed that the main barriers were costs, lack of accessible facilities, information and assistance, physical and psychological issues, as well as bad weather conditions. The key thematic differences in the active group compared with the inactive were: greater interest in physical activity; more likely to have experienced training during rehabilitation or post-discharge; and heightened awareness to types and benefits of physical activity. Among the inactive group, structured programs delivered by trained exercise professionals acted as catalysts to increase their participation, whereas perceived health benefits and community support enhanced their motivation. Results emphasise the importance of information on initiatives that target the SCI population.

Study 2: Following the SCIPA Com intervention, total group (N=64) improvements were significant for LTPA (26 min/day, 95%CI: 16.6 to 35.4; $P < .001$), functional goal achievement (2.0, 95%CI: 1.72 to 2.37; $P < .001$), self-esteem (1.5, 95%CI: .72 to 2.27; $P < .001$), and quality of life domains ($P < .05$). Physical activity adherence rates were greater among the active group (92%, n=27) compared to the previously inactive (50%, n=37) at nine months. The previously inactive group presented significant increases in most outcomes over time, whereas the active group maintained stable results across all assessments.

Study 3: Fifty-eight pairs (clients with SCI and their exercise professionals) were assessed. The physical activity intervention was effective in increasing LTPA levels at three ($P < .001$) and nine months ($P < .05$) follow-up assessments. The hypothesised model provided an excellent fit with the data and reliability estimates supported the internal consistency of the personality attribute scales ($\alpha = .80 - .93$).

Self-perceived positive personality attributes in clients with SCI (e.g. motivation, commitment, self-efficacy, etc.) predicted a significant increase in LTPA levels ($P < .05$) following intervention at three ($r = .28$) and six ($r = .23$) months, with a decrease at nine months ($r = -.14$). Past physical activity behaviour was further significantly associated ($P < .05$) with reduced physical activity levels in months three ($r = .48$), six ($r = .32$), and nine ($r = .28$). At baseline, females ($r = -.30$) and those who sustained SCI ($r = .001$) for longer presented lower LTPA levels at nine months ($P < .05$). Exercise professional self-measurements and other-perceptions of participants with SCI correlated poorly to changes in physical activity over time.

Conclusions

Study 1: Active individuals with SCI revealed the importance of access to information, accessibility, and physical activity opportunities in the community. Perceptions towards barriers and sedentary behaviours were modified (e.g. individuals perceived less barriers and increased LTPA levels) after experiencing a structured physical activity program, especially among those previously inactive. Rehabilitation professionals, SCI networks and health care systems need to intensify the conveyance of information, financial support and equitable opportunities for physical activity during rehabilitation and in the community.

Study 2: The provision of customised physical activity programs for individuals with SCI increased LTPA levels and selected secondary health outcomes. Improvements in LTPA were greater among those physically inactive before participation in SCIPA Com. Follow-up assessments at three and six months post-intervention revealed that improvements in outcomes were maintained above baseline levels. The results support collaborations with community fitness centres for post-discharge maintenance of physical activity levels among people with SCI.

Study 3: Important modifiable attributes identified in this cohort included motivation, confidence, commitment, adaptability, realistic expectations, patience, competitiveness, knowledge on how to exercise and associated benefits. Results from scales developed emphasised the importance of self-perceived positive personality attributes in clients with SCI on the prediction of LTPA levels.

Key Words: spinal cord injuries, motor activity, architectural accessibility, health service accessibility, translational medical research, health promotion, referral and consultation, personality assessment. (MESH terms)

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List of Abbreviations

1RM	one repetition maximum
AAIDD	American Association on Intellectual and Developmental Disabilities
ACC	Accident Compensation Corporation
ACSM	American College of Sports Medicine
ADL	activities of daily living
AG	Active Group
ASI	ASIA Impairment Scale
ASIA	American Spinal Injury Association
B-PADS	Barriers to Physical Activity and Disability Survey
BHADP	Barriers to Health Activities among Disabled Persons
CES-D	Centre for Epidemiological Studies Depression Scale
CVD	cardiovascular disease
CRPD	Convention on the Rights of Persons with Disabilities
DSPQ	Disability Sport Participation Questionnaire
DVT	deep vein thrombosis
EP	exercise professional
EPQR	Eysenck Personality Questionnaire for Extraversion
ESE	Stanford Self-Efficacy for Managing Chronic Disease Scale
FES	functional electrical stimulation
GMBC	Group-Mediated Cognitive-Behavioural Training
GSE	General Perceived Self-Efficacy Scale
HDL	high density lipoprotein
HDL-C	high density lipoprotein cholesterol
I FEEL	I Felt Energy and Emotion in Life
ICF	International Classification of Functioning, Disability, and Health

IG	Inactive Group
ILA	Independent Living Assessments
ISEL	Interpersonal Support Evaluation List
ISNCSCI	International Standards for Neurological Classification of Spinal Cord Injury
LDL	low density lipoprotein
LFS	Lee Fatigue Scale
LTPA	leisure time physical activity
LTPAQ-SCI	Leisure Time Physical Activity Questionnaire for People with Spinal Cord Injury
MMT	manual muscle testing
MVA	motor vehicle accident
NDIS	National Disability Insurance Scheme
NTSCI	non-traumatic spinal cord injury
PAL	personal activity logs
PARA-SCI	Physical Activity Recall Assessment for Individuals with Spinal Cord Injury
PASIPD	Physical Activity Scale for Individuals with Disability
PBC	Perceived Behavioural Control
PEDro	Physiotherapy Evidence Database
PO _{peak}	peak power output
PQOL	Perceived Quality of Life Scale
PTSD	post-traumatic stress disorder
PSFS	Patient Specific Functional Scale
PSS	Perceived Stress Scale
QD	Questionnaire for Depression
QLI	Quality of Life Index
RCTs	randomised control trials

REPs	Registry of Exercise Professionals (New Zealand)
ROM	range of motion
RSS	Rosenberg Self-Esteem Scale
SCI	spinal cord injury
SCIPA	Spinal Cord Injury and Physical Activity project
SCIPA Com	Spinal Cord Injury and Physical Activity in the Community program
SF-36	Short-Form 36-Item Health Survey
SMART	specific, measurable, attainable, realistic, and time specific
SRAHP	Self-Rated Abilities for Health Practices Scale
STAI-X2	The State-Trait Anxiety Inventory, Form X2
STATA	Data Analysis and Statistical Software
TAC	Transport Accident Commission
T3-SCI	Train the Trainers Spinal Cord Injury Course
TSCI	traumatic spinal cord injury
UN	United Nations
UTI	urinary tract infection
VIA	Values in Action Project
VIA-IS	VIA Inventory of Strengths
VO _{2peak}	peak oxygen uptake
WHO	World Health Organisation
WHOQOL-BREF	World Health Organisation Quality of Life Questionnaire Abbreviated-Version

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Chapter 1: Introduction

This thesis contains seven chapters, with a detailed description of studies within the Spinal Cord Injury and Physical Activity in the Community program (SCIPA Com) through chapters three to five:

Chapter 1 Introduction addressing the gaps in literature, research questions, objectives and hypothesis of the studies.

Chapter 2 Review of the literature concerning SCI, health consequences, rights to health services, and benefits of physical activity.

Chapter 3 *Study 1*, Barriers and Facilitators to Physical Activity among Individuals with SCI, which explores factors that represent barriers or facilitators for physical activity among individuals with SCI.

Chapter 4 *Study 2*, the Spinal Cord Injury and Physical Activity in the Community program (SCIPA Com), a safe and structured community-based leisure time physical activity program.

Chapter 5 *Study 3*, Analysis of Positive Personality Attributes in Clients as Predictors of Physical Activity, consisting of the identification of personality attributes among exercise professionals and clients with SCI, as well as their influence on leisure time physical activity levels.

Chapter 6 General discussion of findings and implication of the three studies comprised in this thesis. Finally,

Chapter 7 Conclusions drawn from our investigations.

Studies within the Spinal Cord Injury and Physical Activity in the Community program (SCIPA Com) were conducted from November 2011 to November 2013, based on a mixed-methods design of evaluation models.

The first study focuses on the exploration of barriers and facilitators to leisure time physical activity (LTPA i.e.: wheeling, playing sports, or exercising at fitness centre, other than their daily activities that involve manual wheelchair use for mobility, occupational activity, or incidental activity) (Martin Ginis et al., 2010e) among individuals with spinal cord injury (SCI) in Australian and New Zealander community fitness centres. The perceived positive personality attributes of exercise professionals and participants with SCI in regards to physical activity behaviour were also examined. Part of the information collected was used to develop scales for self- and other-assessments of personality attributes in later stages of research.

The second study is a quasi-experimental investigation conducted to analyse the outcomes of SCIPA Com, a customised eight-to-twelve week physical training program involving exercise professionals and clients with SCI. SCIPA Com comprised three stages. Stage 1 involved risk management and training exercise professionals via the *Train the Trainers Spinal Cord Injury® (T3-SCI®)* course; which led to Stage 2, the implementation of physical activity programs in community fitness centres for clients with SCI; and Stage 3, follow-up assessments for four different aspects, namely 1) changes in LTPA levels, 2) specific functional goal achievements, 3) self-esteem, and 4) quality of life.

The third study was an assessment of positive personality attributes deemed important in increasing LTPA levels among individuals with SCI. Positive personality attributes towards a physically active lifestyle were identified and measured to determine the association between self-perceived and other-perceived personality strengths and physical activity levels.

1.1 BACKGROUND

The spinal cord is commonly perceived as a part of the central nervous system that simply transfers motor and sensory information between the body and brain. A more comprehensive physiological examination reveals that the spinal cord, brain and brainstem originate from a common progenitor and are one continuous structure forming the central nervous system (Hochman, 2007). In addition to

complex somatosensory integration, the spinal cord shares many other functions with the brainstem such as postural/movement control and autonomic function of the human body (Hochman, 2007).

A spinal cord injury (SCI) is a highly debilitating condition with profound physical, psychological, and social impact on a person's life (World Health Organization, 2013). It is often followed by permanent loss of function, serious secondary complications, increased health care costs, and community exclusion (Ackery, Tator, & Krassioukov, 2004; McDonald & Sadowsky, 2002; O'Connor, 2005a, 2005c; Walsh, Dayton, Cuff, & Martin, 2005; Wyndaele & Wyndaele, 2006). Severity of a SCI is predominantly assessed following the American Spinal Injury Association Impairment Scale (ASIA) which has guided clinical prediction of motor recovery and rehabilitation methods (Kirshblum et al., 2011). Two categories are widely used to describe different levels of SCI: Tetraplegia (impairment or loss of motor and/or sensory function in the cervical segments of the spinal cord typically resulting in impaired function of arms, trunk, legs and pelvic organs i.e. all four extremities) and Paraplegia (impairment or loss of motor and/or sensory function in the thoracic, lumbar, or sacral segments of the spinal cord with consequential impairment of the trunk, legs, and/or pelvic organs depending on the level of injury) (Kirshblum et al., 2011).

Along with neurological deficits and disabilities, individuals with SCI present serious comorbidities such as urinary tract infections, reduced bowel motility, and other physiologic complications of the cardiac, respiratory and metabolic systems (Silva, Sousa, Reis, & Salgado, 2013). Many have also been experiencing age related complications due to increased life expectancy in SCI population in high-income countries, living close to a normal life span (Yeo et al., 1998). A review on psychosocial issues in people with chronic SCI highlighted increased rates of depression, anxiety and post-traumatic stress disorder (PTSD), as well as a reduced average life satisfaction compared to the general population (Post & van Leeuwen, 2012).

The treatment of SCI and associated problems traditionally aims to assist people with SCI in achieving maximum independence through compensatory functional activities (e.g. wheelchair skills and assisted walking), strengthening of muscles with voluntary control, and stretching exercises (Behrman & Harkema, 2007; Kirshblum et al., 2011; Taylor-Schroeder et al., 2011; van Langeveld et al., 2011). Additional measures are also implemented to prevent injury progression such as management of spasticity, autonomic dysreflexia, pain, bowel and bladder

regimes, and coping mechanisms (Silva et al., 2013). Evidence suggests that recent advances in acute care are resulting in a greater longevity (Middleton et al., 2012; Wuermsler et al., 2007) and higher proportions of incomplete SCIs (Burt, 2004). At least 41 recent neurobiology studies have reported strategies for SCI repair (Silva et al., 2013). These ongoing investigations are shifting the focus of rehabilitation professionals from palliative care onto maintenance of optimum health and fitness through physical activity to enable future treatments (Galea, 2012; Guest, Santamaria, & Benavides, 2013; Liu et al., 2010).

Since the 1930s, accumulating data suggest that structured physical activity is associated with better fitness and health, and this has been reinforced to help prevent secondary health problems and enhance functional abilities, self-esteem, quality of life, and community integration (Fullerton, Borckardt, & Alfano, 2003; Jacobs & Nash, 2004; Myslinski, 2005; Nash, 2005). Additional benefits can be obtained through the increased production of neurotransmitters (i.e. serotonin, norepinephrine, and dopamine) that help regulate emotion and prevent or alleviate depression (Martin Ginis et al., 2010a; Martin Ginis, Jetha, Mack, & Hetz, 2010d). Potential cost savings of early prevention/intervention are also associated with reduced expenses of hospitalisations, powered mobility aids, and additional personal attendant care (Ackery et al., 2004). The increased risk of secondary complications and elevated costs associated with SCI and ageing represent a great concern to their families and government; fortunately, these issues can be reduced with adequate levels of physical activity (Hetz, Latimer, & Martin Ginis, 2009; Hicks et al., 2003; Martin Ginis et al., 2010e).

Nevertheless, people who sustain this condition are less likely to participate in a physically active lifestyle in their community when compared to the able-bodied population (Kehn & Kroll, 2009). An extensive epidemiological study from Canada detected that only 50% of the people living with SCI engaged in physical activity, for an average of 27 minutes per day, while the other half reported no involvement with LTPA (Martin Ginis et al., 2010e). This ranks people with SCI at the bottom of the physical activity spectrum, being susceptible to increased morbidity and mortality (Kehn & Kroll, 2009). Several barriers lead to reduced levels of physical activity and, in some circumstances, community participation (Lannem, Sørensen, Frøslie, & Hjeltnes, 2009; Maynard et al., 1997; Scelza et al., 2007; Schopp et al., 2007). Such obstacles are essentially related to wheelchair access and lack of personal assistance to execute the activities within community fitness centres (Kehn & Kroll, 2009). These barriers need to be addressed through the provision of affordable

facilities with qualified exercise professionals to deliver accessible, inclusive, and equitable physical activity support for community-dwelling individuals with SCI (Kehn & Kroll, 2009; Rimmer & Marques, 2012). Hence, it is crucial to identify and understand factors that lead to current high inactivity rates and facilitators for physical activity improvement and adherence.

Previous studies have determined important strategies that enhance adherence to physical activity, for instance, by outlining exercise plans and schedules supplemented with coping plans, which involve the anticipation and strategy development to overcome potential barriers (Arbour-Nicitopoulos, Martin Ginis, & Latimer, 2009; Brawley, Arbour-Nicitopoulos, & Martin Ginis, 2013; Hicks et al., 2003; Latimer-Cheung et al., 2013). Investigations were predominantly undertaken in clinical/research institutions and have not been able to directly influence the business model of the health and fitness industry in the community. In fact, an Australian study detected the lack of SCI expertise among health providers in the community (Cox, Amsters, & Pershouse, 2001).

To the best of our knowledge, no studies in current literature have focused on the reduction or elimination of important barriers that impede physical activity in community fitness centres; nor have perceptions towards barriers and facilitators been examined to detect changes after exposure to a structured physical activity program. Positive personality attributes among people with SCI and exercise professionals have not been investigated although they may underpin the success of important health outcomes (Park & Peterson, 2009). Information regarding these issues can make a significant contribution to community integration of people with SCI in health and fitness facilities and promote awareness of perceived barriers and facilitators towards ongoing physical activity participation.

This translational study is the first to adopt an educational and risk management approach to integrate a public health initiative truly within the community of a person with SCI. The development process of our research is displayed in **Figure 1.1**. We examined the effectiveness of evidence-based training programs for people with SCI assisted by exercise professionals capable of delivering appropriate and safe physical activity programs, and further probing intra and inter-personal research of Positive Psychology concepts for physical activity enhancement.

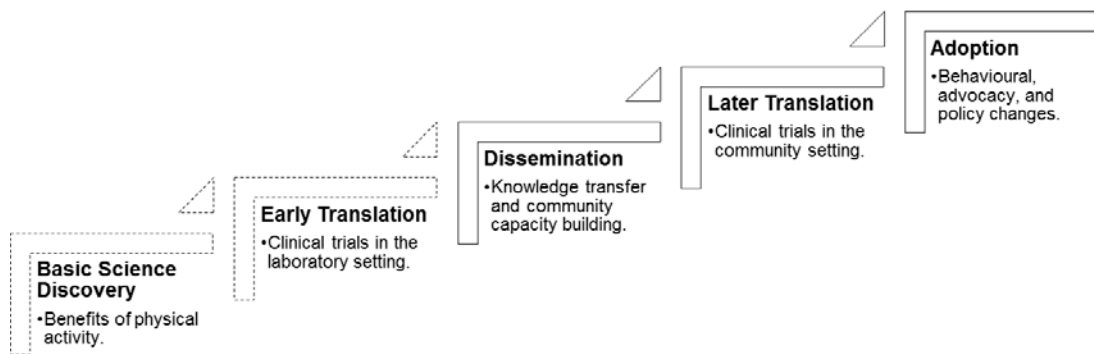


Figure 1.1. Translational research “step” process within this thesis. The upper three steps (continuous lines) were undertaken by the present research. Procedures under dotted lines steps (lower steps) are other forms of studies in scientific literature.

The selection of community health and fitness centres was defined by a concordance of a) acceptance of the facility managers in adopting the SCIPA Com model for their business; b) interest of exercise professionals in receiving training and working with clientele with SCI; and c) willingness of people with SCI to engage in physical activity in their local community gym. Motivational measures such as reduced costs for people with SCI to access fitness centres and ongoing support for exercise professionals were delivered. The clients’ physical strengths, personality attributes, and personal goals were also incorporated into the development of training programs. The educational component offered to exercise professionals envisioned adaption and delivery of physical activity programs for people with SCI considering their specific requirements and paramount issues of safety. Expansion and implementation of this model in several community-based fitness centres was aimed to provide individuals with SCI readily access to physical activity facilities and expertise across Australia and New Zealand.

1.2 RESEARCH QUESTIONS

This research thesis investigated barriers and facilitators for physical activity among individuals with SCI living in community fitness centres of Australia and New Zealand. Secondly, the national SCIPA Com program informed health service providers on safe and effective physical activity programs for individuals with SCI through the *Train the Trainers Spinal Cord Injury® (T3-SCI®)* course. This course was followed by the implementation of tailored physical activity programs with multiple follow-up assessments to examine whether the programs increased levels of activity, functional goal achievement, self-esteem, and quality of life over four specific time periods (baseline and follow-ups after 3, 6, and 9 months). Part of this assessment incorporated an intra- and inter-personal analysis of positive personality attributes between exercise professionals and individuals with SCI for the prediction and encouragement of physical activity behaviour.

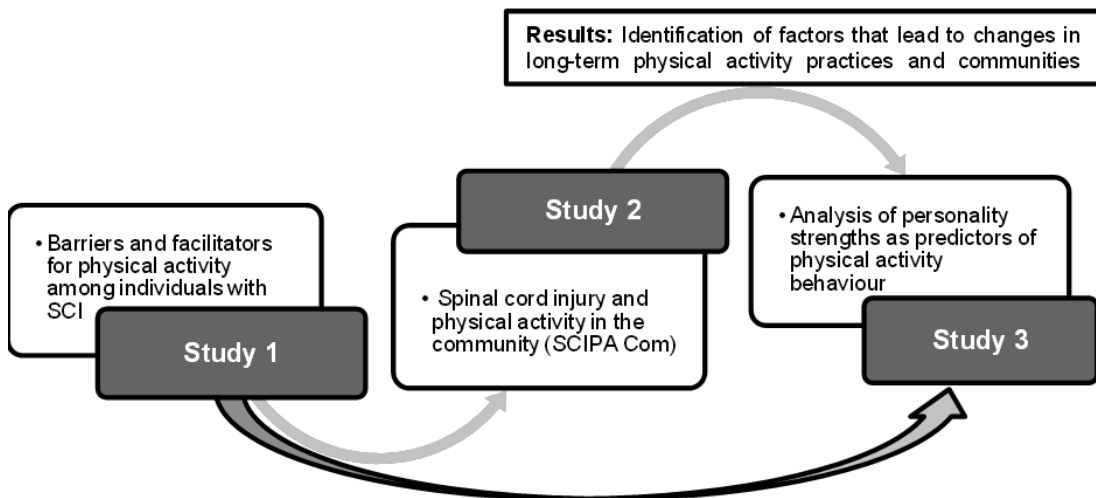


Figure 1.2. The conceptual inter-relationship between the three studies comprising the Spinal Cord Injury and Physical Activity in the Community program (SCIPA Com).

1.3 SPECIFIC QUESTIONS

Inconclusive findings in literature related to individuals with SCI living in Australian and New Zealander communities led to the following questions:

Study 1 (Chapter 3)

- What are the barriers that limit individuals with SCI from performing physical activity in the communities of Australia and New Zealand?
- What facilitates physical activity participation of people with SCI within the communities of Australia and New Zealand?
- Are there any differences between the barriers and facilitators perceived by highly active individuals with SCI compared to inactive individuals?
- Do perceptions on barriers and facilitators for physical activity change after being exposed to a structured physical activity program?

Study 2 (Chapter 4)

- Do structured physical activity programs in the community increase physical activity levels of people with SCI?
- Do physical activity levels correlate to functional goal achievement, self-esteem, and quality of life?
- Are there differences between the outcomes of highly active individuals compared to inactive people with SCI?
- Do individuals with SCI adhere to long-term physical activity after participating in a structured program in the community?

Study 3 (Chapter 5)

- From the perspective of people with SCI, which positive personality attributes are considered important for the enhancement of LTPA levels among individuals with SCI?
- From the perspective of exercise professionals, which positive personality attributes are considered important for the enhancement of LTPA levels among individuals with SCI?
- In a SCI/exercise professional context, do self- and other-perceptions of positive personality attributes impact on LTPA levels after a structured physical activity program based on their goals, personality attributes and physical strengths?

Chapter 2: Literature Review

This review of literature contains the following sections:

Section 2.1 Overview of the anatomical and physiological features of the spinal cord.

Section 2.2 Review of the literature on the characteristics and consequences of SCI.

Section 2.3 Information on the human rights of people with disabilities in accessing health services.

Section 2.4 The stages of SCI rehabilitation.

Section 2.5 Benefits of physical activity in the health maintenance phase of individuals with SCI.

Section 2.6 Adherence strategies towards physical activity.

Section 2.7 Barriers and facilitators for physical activity among individuals with SCI.

Section 2.8 The use of Positive Psychology and personality attributes assessments to predict and encourage physical activity behaviour among individuals with SCI.

Section 2.9 Summary and implications of physical activity in individuals with SCI and the conceptual framework for the three dissertation studies included in this thesis.

Section 2.10 Reiteration of the objectives of each of the three studies within this thesis. And

Section 2.11 Hypotheses drawn from the literature reviewed.

2.1 SPINAL CORD

The spinal cord is a thin longitudinally oriented bundle of neurons that occupies the spinal canal (Kirshblum et al., 2011). It extends from the occipital bone level to the first or second lumbar vertebrae, where it is continued by the *cauda equina*. A cross-sectional view reveals an elliptical formation of 0.5-2 cm diameter with a grey “butterfly” figure formed by the body of neurons, enclosed by white motor and sensory tracts. It is protected by the spinal column, intervertebral discs and ligaments. Thirty-one pairs of spinal nerves exit the spinal cord through intervertebral foramina to innervate the different physiological systems of the human body. Each pair corresponds to a neurological segment divided into eight cervical, twelve thoracic, five lumbar, five sacral and one coccygeal levels (displayed on **Figure 2.1.**). They are commonly referred to by the first letter and number of each neurological level, e.g. the first cervical neurological level is represented by C1.

Each spinal nerve presents two roots: a dorsal sensory root and a ventral motor root. The sensory axons innervate specific areas of the skin called dermatomes and the motor axons provide innervation to a collection of muscle fibres named myotomes. There are 28 dermatomes and 10 myotomes mapped according to which segment of the spinal cord they refer to. They are used on the examination of the most distal sensory and motor levels preserved in cases of SCI, on both left and right side of the body (Kirshblum et al., 2011).

2.2 SPINAL CORD INJURY (SCI)

SCI is defined as “damage to cells in the spinal cord or nerve tracts that relay signals up and down the spinal cord” (Kent, 2006). For the present thesis, lesions to the spinal cord, *conus medullaris* and *cauda equina* were considered as SCI (World Health Organization, 2013). The aetiology of a SCI is classified as either traumatic or non-traumatic. Traumatic causes vary world-wide, commonly including motor vehicle accidents, falls, violence, recreational activities, and iatrogenic injuries (McDonald & Sadowsky, 2002). SCIs of non-traumatic nature are categorized under congenital, genetic, metabolic, and acquired abnormalities (New & Marshall, 2014). The prevailing non-traumatic conditions are spinal neoplasms, stenosis, vascular

and autoimmune diseases (Cosar et al., 2010; Gupta, Taly, Srivastava, & Murali, 2009; Ho et al., 2007).

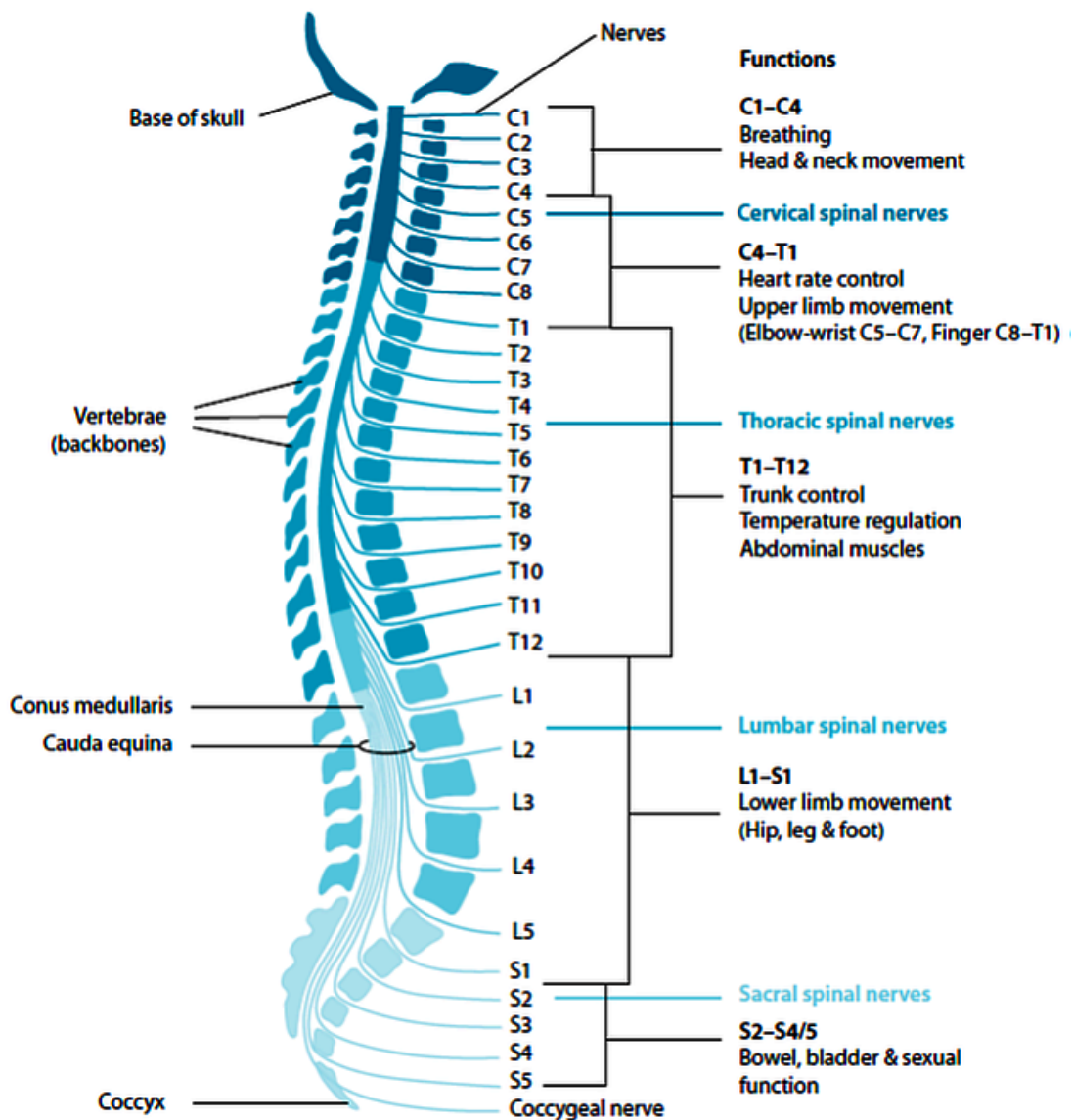


Figure 2.1. "Figure 1.1. Longitudinal organization of the spinal cord (with cervical, thoracic, lumbar and sacral segments shaded), spinal vertebrae, and spinal nerves and a rough representation of major functions of the spinal cord." Reprinted from *International perspectives on spinal cord injury* (p. 5), by the World Health Organisation, 2013, Geneva: World Health Organisation Press. Copyright 2013 by the World Health Organisation.

According to McDonald & Sadowsky (2002), the onset of a traumatic SCI presents two main stages: primary and secondary injury. Primary injury is the direct impact or compression to the spinal cord by foreign objects or unstable bone fragments and disc elements. Resulting damage to blood vessels and swelling increase the compression on the spinal cord that leads to progressive secondary

ischemia, the spinal neurogenic shock phase. Affected neural cells generate excitotoxicity that spread the insult to healthy surrounding neurons. Secondary injury is installed upon hypoperfusion initiated in the grey matter to the white matter, which blocks the propagation of action potentials by axons and exacerbates neurogenic shock.

The progression of non-traumatic SCIs is disease-specific, though also presenting primary and secondary phases. Similar to traumatic injuries, damaged neural cells due to non-traumatic SCIs excrete toxic chemicals that destroy neighboring neurons and oligodendrocyte and impede the transmission of neural impulses (McDonald & Sadowsky, 2002).

A comprehensive report from The World Health Organisation (Australian Human Rights Commission) lists complex and intertwined elements that determine the effects of SCI on an individual's life. They include biological factors, age of onset, aetiology, location, extent of the injury, and availability of resources upon and throughout the progression of a SCI. The environment in which a person is embedded plays a determinant role on the clinical characteristics of a SCI; whether it imposes physical and social barriers or facilitates rehabilitation and community outreach.

2.2.1 Clinical presentations

SCI can cause permanent complete or incomplete loss of bodily sensory functions and controlled motor abilities at the level of and below the injury. The *International Standards for Neurological Classification of SCI (ISNCSI)* use two generic terms to describe clinical presentations of SCIs: paraplegia and tetraplegia.

Paraplegia and tetraplegia

Paraplegia is the motor and/or sensory disruption to thoracic (T2 to T12), lumbar (L1 to L5), and sacral (S1 to S5) neurological segments of the spinal cord. It causes paralysis and/or anaesthesia to the trunk, pelvic organs, and lower limbs. If the damage is situated on the sixth thoracic spinal nerve or above, a SCI may also lead to loss of autonomic regulation of vital physiological of the respiratory, cardiovascular, thermoregulatory, urinary, digestive, and sexual systems.

Tetraplegia is caused by an injury to cervical neurological segments of the spinal cord (between C1 and T1). It results in paralysis and/or anaesthesia of the

upper limbs, trunk, pelvic organs, and lower limbs. Autonomic dysregulation is common in these cases and people with lesions on or above the fourth cervical neurological level may require ventilatory support.

Complete and incomplete

The words “complete” and “incomplete” injuries are also further used to help describe the severity of the condition. SCI is classified as complete in the absence of sensory or motor functions on the lowest sacral neurological segments S4-S5. Incomplete injuries present preserved sensory and motor functions below the level of injury due to the partial conservation of tracts and function in the spinal cord. Complete lesions to upper segments of the spinal cord will result in higher levels of impairment, while incomplete injuries at any level present an array of clinical presentations depending on the extent of the lesion.

Neurological level of injury

Systematic clinical assessments of sensory and motor levels help determine neurological level of injury. This is identified as the most distal portion of the spinal cord that presents intact sensory and motor functions of the left and right side of the body. It is often used to determine the prognosis and clinical characteristics of a SCI.

ASIA Impairment Scale (AIS) (modified from Frankel)

The *American Spinal Injury Association (ASIA)* developed the *Impairment Scale (AIS)* to determine the extent of the impairment with more precision. The levels range from the most severe (A) to normal sensation and motor function (E):

(A) *Complete*. When no motor or sensory functions are preserved below S4-S5;

(B) *Sensory incomplete*. In cases where sensory functions are intact, without presenting motor function below the neurological level of injury, including S4-S5;

(C) *Motor incomplete*. In the event of preserved motor functions below the neurological level of injury with more than half of the key muscles presenting muscle grade between 0 and 2;

(D) *Motor incomplete*. Condition in which motor function is present below the neurological level of injury and at least half of the key muscles are graded 3 and over;

(E) *Normal*.

Zones of partial preservation (ZPP)

ZPPs can be found in complete injuries with partially innervated dermatomes and myotomes below the SCI level.

Clinical Syndromes

Incomplete syndromes are often described in literature, though they are not used by the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI). They are referred to as the central cord, Brown-Sequard, anterior cord, cauda equina, and conus medullaris syndromes.

Central cord syndrome. Incomplete injury that affects predominantly the upper limbs. It is the most common syndrome and frequently results from cervical spondylosis due to a hyperextension injury (falls).

Brown-Sequard syndrome. Hemisection of the spinal cord causing sensory loss on the level of injury; ipsilateral loss of proprioception, vibration, motor control below the lesion; and contralateral loss of pain and temperature sensation below the injury level. It is rare form of lesion often associated to knife wounds.

Anterior cord syndrome. Damage to the corticospinal and spinothalamic tracts. This leads to loss of voluntary motor function, as well as nociception and temperature sensation at and below the injury level. The dorsal columns are spared preserving the sensation of light touch and proprioception.

Cauda equina syndrome. Injury to the lower motor neurons of the cauda equina without affecting the spinal cord. This syndrome is characterised by flaccid paralysis of the lower limbs, areflexia, and incontinence, typical of lower motor neuron lesions.

Conus medullaris syndrome. Injury to the lower levels of the spinal cord, such as L1-L2. They may present upper motor neuron symptoms (increased spasticity), lower motor neuron symptoms (flaccidity), or a mix of both.

2.2.2 Epidemiology and costs

SCI affects approximately 0.1% of individuals world-wide (World Health Organization, 2013). Though prevalence is relatively not high, it is one of the most expensive and time consuming disorders to treat (Ackery et al., 2004). In fact, the quality of SCI care is a great indicator of the countries' overall health care systems because individuals with SCI experience all clinical settings available through a long period of time and can help identify the gaps in the system (World Health Organization, 2013). Epidemiological data also vary from country to country regarding SCI prevalence and incidence, main causes, demographic characteristics of those affected, clinical presentation, and associated costs.

Incidence and prevalence

International incidences of SCIs lie between 250 000 and 500 000, that is 40 to 80 new cases per million population every year (World Health Organization, 2013). In developed countries, the incidence is lower, being between 112,000 to 273,000, that is 16 and 39 per million inhabitants yearly (Wyndaele & Wyndaele, 2006). Australian data estimate that approximately one person per day suffers a traumatic SCI, resulting in 14.9 per million cases every year (Cripps, 2009), whereas in New Zealand approximately one SCI is registered every five days (i.e. 30 per million). The incidence rates in New Zealand are higher for Māori (46 per million), and Pacific (70 per million) people, relative to Europeans (29 per million) (Derrett et al., 2012).

Generally, a greater proportion of traumatic injuries are reported compared to non-traumatic. Data from 2011 registered a prevalence of 236–1009 cases of SCI per million inhabitants due to traumatic causes alone (Cripps et al., 2011). Similar to global statistics, traumatic injuries are more common in Australia in comparison to non-traumatic. Studies show a prevalence of 681 per million cases of traumatic (O'Connor, 2005c) and 455 per million of non-traumatic SCIs throughout the country (New, Farry, Baxter, & Noonan, 2013). These current figures illustrate an increasing proportion of non-traumatic SCIs and an aging Australian population that require more expensive care (World Health Organization, 2013).

Among traumatic SCIs, studies highlight motor vehicle accidents (MVAs) as the leading cause in early adulthood, followed by falls prevalent in the elder population (Ackery et al., 2004). According to the World health Organisation (2013), road traffic accidents are responsible for 40 to 70% of all SCI cases; 14 to 40% of

the cases occur from falls; violence is the third largest cause of SCI and it is country-specific or related to war zones; and sports injuries cause less than 10% of SCI world-wide. They are more frequent between the ages of 20 and 40, affecting mainly men (m:f, 3-4:1) (Ackery et al., 2004; Wyndaele & Wyndaele, 2006). In Australia, the main cause of SCI continues to be MVAs (52.4%), followed by falls (28.8%), collision (with a person or object: 8.1%), and water-related injuries (diving or surfing: 7.7%); these figures are similar to New Zealand's main cause of SCI (38.9% due to land transport-related MVAs) (Derrett et al., 2012). The predominant demographic characteristics of people with SCI in Australia consist of males (83%), with average age of 42 (SD \pm 19) years for traumatic cases, though most acquired their injuries around the ages of 15 to 24 (Cripps, 2009). Nonetheless, in the three past decades researchers have been observing a growing pattern of incomplete cervical injuries among the elder mainly caused by falls (DeVivo & Chen, 2011; Ho et al., 2007).

The prevalence of non-traumatic SCIs is difficult to estimate due its heterogeneous nature and lack of an efficient registry system (Cripps et al., 2011). The main causes recorded are spinal neoplasms, degenerative conditions, vascular and autoimmune diseases (Cosar et al., 2010; Gupta et al., 2009; Ho et al., 2007). Non-traumatic SCIs are more common among males and present strong correlation to advanced age (New et al., 2013). Prevalence studies in Australia show slightly higher rates of males with an average age of 52 (SD \pm 16) years (Cripps, 2009; Cripps et al., 2011) presenting incomplete paraplegia (New et al., 2013). Interestingly, a profile compiled by the US National Spinal Cord Injury Statistical Database revealed more females of older age developing incomplete paraplegia due to non-traumatic causes (Cosar et al., 2010).

Prevalence of clinical presentation of SCI

Regarding the predominant classification of SCIs, researchers have reported conflicting data. Wyndaele & Wyndaele (2006) stated that the two thirds of SCIs are classified as paraplegia with 50% of them complete injuries; another study by Ho et al. (2007) observed more cervical injuries throughout the same period, classifying 56% of the cases as tetraplegia. In 2009, the Australian Institute of Health and Welfare reported more cases of incomplete tetraplegia (34%) than any other type of SCI; the second most prevalent presentation was incomplete paraplegia (25%), followed by complete paraplegia (25%) and complete tetraplegia (16%) (Cripps, 2009).

Costs of SCI

Expenditures associated to SCI care in Australia add up to a total of \$ 2 billion dollars (AUD) a year of costs (Access Economics Pty Limited, 2009). Expenses are higher for people with tetraplegia due to traumatic causes, reaching 9.5 million Australian dollars on SCI related care during their lives, whereas individuals with paraplegia spend a total of 5 million Australian dollars (Access Economics Pty Limited, 2009). These figures are similar to the amount estimated in Canada and lower than the \$ 9.7 billion (\$US) expended on the treatment of SCI per year in the United States of America (Ackery et al., 2004; Krueger, Noonan, Trenaman, Joshi, & Rivers, 2013). Rates are especially elevated during the first year of the SCI as a result of acute interventions and investment in adapted equipment and assistance (DeVivo, Chen, Mennemeyer, & Deutsch, 2011). More importantly, indirect costs associated to medical and rehabilitation services, as well as loss of productivity imposes a substantial economic burden on health care systems and patient's families throughout an extended period of time (Cao, Chen, & DeVivo, 2011).

Mortality and life expectancy

Mortality risk and life expectancy are country-dependent. Developed nations have demonstrated a substantial increase in the life expectancy of individuals affected by SCIs since the early 50s. These advances shifted the causes of death from infections due to urinary tract infections and pressure sores to age-related ailments, such as respiratory and cardiovascular diseases (World Health Organization, 2013). Septicaemia was found to be the main causes of mortality. Meanwhile, developing countries have not had similar improvements and deaths are still attributed to preventable causes. According to Krause, DeVivo, and Jackson (2004), other strong predictors of longevity after SCI include age of injury, neurological level of injury, completeness of the injury, ventilator dependency, number of hospitalisations, poor health status, and social factors. The same authors found that mortality odds increase up to 40 times in cases of high cervical lesions, classified as ASIA grade A, and requiring mechanical ventilation. High risk behaviours, poor self-care practices, and psychological issues may also increase the mortality risks among individuals with SCI. This study observed higher odds ratio (OR) of mortality in people admitted to hospital care (OR = 1.78, $P < .001$), with poor health (OR = 1.74, $P = .002$), and in those that developed a grade 3 or 4 pressure ulcer (OR = 1.74, $P = .01$). In contrast, community integration reduced mortality rates by an average of 33.5%.

A retrospective study performed in Australia revealed that the mortality rates are highly associated to the extent of the injury. Though survival rates among people with tetraplegia AIS A-C presented the most significant increase over the past 50 years, they are still more likely to die within the first year (8.2% of a total of 2014 individuals with SCI) and, from the survivor pool, 47% present a 40-year survival rate post SCI (Middleton et al., 2012). Individuals with paraplegia have higher survival rates, approximately 62%.

2.2.3 Health consequences of SCI

In addition to diminished sensory-motor control, SCIs have extensive impact on all physiological systems of the body. Changes have been reported to cardiovascular, metabolic, respiratory, thermoregulatory, dermatologic, musculoskeletal, immune, genitourinary, and gastrointestinal systems (McColl, Aiken, McColl, Sakakibara, & Smith, 2012; McDonald & Sadowsky, 2002; World Health Organization, 2013). In general, people with SCI may present several complications associated with impaired autonomic regulation and physiological systems of the body. Furthermore, psychosocial issues also impact on the evolution of aetiologies related to behavioural and self-care practices (Krause et al., 2004).

Changes to the cardiovascular system

Sympathetic regulation of the cardiovascular system derives from T1-L2 spinal segments (Grigorean et al., 2009). SCIs above and including the spinal segment T6 cause sympathetic hypoactivity due to disruption of supraspinal control, as well as unopposed vagal parasympathetic tone (Teasell, Arnold, Krassioukov, & Delaney, 2000). The consequences are decreased cardiac contractility and reduced vasomotor tone below the lesion. Clinical manifestations include bradycardia and lower resting arterial pressure; impaired cardiovascular response to physical activity; autonomic dysreflexia; orthostatic hypotension; increased risks of cardiovascular diseases (Cragg, Noonan, Krassioukov, & Borisoff, 2013c); deep vein thrombosis; and in severe cases, cardiac arrest (Lavis, Scelza, & Bockenek, 2007; Teasell et al., 2000).

Autonomic dysreflexia. Autonomic dysreflexia is a sudden increase of arterial blood pressure with compensatory bradycardia in response to noxious or non-noxious stimuli below the level of injury, especially in cases of SCIs above and including level T6 (Krassioukov, Warburton, Teasell, & Eng, 2009). Noxious stimuli

can be triggered by various conditions, the most common being distended bladder or colon, obstructed urinary catheters, and skin lesions. Once activated, nociceptors normally emit afferent impulses that ascend the dorsal columns and spinothalamic tract. A SCI prevents these signals from reaching cortical levels for supraspinal inhibitory control. Instead, impulses activate the intermediolateral column of the spinal cord which leads to a sympathetic activity outflow below the level of injury, exacerbated by hyper-responsiveness of peripheral receptors (Teasell et al., 2000). Consequent vasoconstriction and hypertension within the arterial system and cerebral vasodilatation are detected by the brain through baroreceptors and IX and X cranial nerves. The parasympathetic system is then stimulated to reduce heart rate levels to counteract hypertension, though once again these descending signals are obstructed by the SCI, deterring the regulation of blood pressure (Grigorean et al., 2009). Other signs and symptoms of autonomic dysreflexia include migraines, visual distortion, hyperhidrosis above the lesion, and piloerection (Grigorean et al., 2009). It is a serious condition that if left unresolved may lead to cerebral vascular accidents, myocardial ischemia, seizures, and death (World Health Organization, 2013).

Orthostatic hypotension. Orthostatic hypotension is commonly present due to impaired sympathetic efferent activity and absence of arterial and venous vasoconstriction to adjust blood pressure when moving from lying to the upright position (Teasell et al., 2000). Blood volume is sequestered in the lower extremities which then decreases end-diastolic filling volumes to supply the central nervous system with arterial blood and oxygen. Common signs are dizziness, nausea, fatigue, and temporary loss of consciousness (World Health Organization, 2013).

Deep vein thrombosis (DVT). Immobility and alterations to the vascular system are the main causes of DVT and thromboembolism development among people with SCI (Chiodo et al., 2007). The initial signs and symptoms of DVT are swelling, increased temperature, pain, and skin discoloration of the limb (World Health Organization, 2013). DVTs may be life threatening if not treated immediately with anticoagulant and the risk is increased by age and lifestyle choices such as smoking, lack of physical activity, and use of contraceptives (Burt, 2004; Chiodo et al., 2007).

Cardiovascular disease (CVD). A recent study conducted by Cragg et al. (Australian Human Rights Commission) determined a higher risk rate for cardiovascular diseases among the SCI population. People with SCI were 2.72 (CI 1.94-3.82) times more susceptible to heart dysfunctions, such as coronary heart

diseases, and had 3.72 (CI 2.22-6.23) more chances of having a stroke compared to the general population (Cragg et al., 2013c). Increased risk is attributed to numerous factors such as physical inactivity, autonomic deregulation, diminished glycaemic control, unbalanced lipid levels, changes in body composition, male gender, advanced age, higher levels and severity of SCI (Cragg et al., 2013c; Grigorean et al., 2009; Lavis et al., 2007).

Changes to metabolism

Reduced resting metabolic rate, abnormal lipid profiles, changes in body composition, and insulin resistance are often present with SCI (Lavis et al., 2007). Absolute resting metabolic rate of a person with SCI is approximately 10 to 30% lower in comparison to an able-bodied person (Buchholz, McGillivray, & Pencharz, 2003). Individuals with SCI are also prone to lower high-density lipoproteins cholesterol (HDL-C) (41 mg/dL versus 49.6mg/dL, $p < .001$) and higher total cholesterol/HDL-C ratios (4.5 versus 4.0, $P = .002$) compared to able-bodied individuals (Gilbert et al., 2014). These factors, along with hypertension and relative obesity, comprise the metabolic syndrome highly correlated to increased risk of cardiovascular diseases (Gilbert et al., 2014; Lavis et al., 2007). Biochemical changes are installed shortly after SCI promoting increased bone reabsorption and osteoporosis (Dionyssiatis, 2011).

Glucose tolerance and type 2 diabetes mellitus. Wheelchair dependency and sedentary lifestyle exacerbate muscles atrophy and weight gain following a SCI (Lavis et al., 2007). Reduced peripheral muscle mass is particularly detrimental for the metabolism of glucose, which is compensated by increased insulin levels. Overtime, body adiposity and glucose tolerance may lead to type 2 diabetes. Studies have reported a 2.45 (95% confidence interval 1.34 to 4.47) increased risk in acquiring diabetes compared to able-bodied counterparts (Cragg et al., 2013a).

Osteoporosis. Paralysed limbs suffer a rapid decline of bone mineral density and trabecular disorganisation subsequent to a SCI (Dudley-Javoroski, Amelon, Liu, Saha, & Shields, 2013; Gifre et al., 2014). Demineralisation mainly occurs in trabecular bone compartments, such as epiphyses of femurs and tibias (Dionyssiatis, 2011). The pathogenesis of osteoporosis is not fully understood, though recent studies have hypothesised an “SCI-induced osteoporosis” (Jiang, Jiang, & Dai, 2006). Beyond disuse and unloading of paralysed limbs, individuals with SCI undergo accelerated bone mineral density reduction due to disrupted

vasoregulation, tissue oxidation, and parathyroid gland dysfunction. A 10-year follow-up study in Spain identified that in a sample of 129 patients, 25% developed fractures after 6.4 (SD \pm 2.4) years of SCI onset, predominantly associated to low-impact injuries (Gifre et al., 2014). The risk was at its highest among people with complete SCI who sustained their injury for longer periods (> 6 years).

Changes to the respiratory system

The impact of SCI on the respiratory system is dependent on the level of injury: above and inclusive of C3 may require mechanical ventilation; C5 and above affects innervation and function of the diaphragm (primary muscle of respiration supplied by phrenic nerve roots C3-C5) and leads to decreased total lung capacity (TLC) and forced vital capacity (FVC); high paraplegia (T1-T6) can paralyse accessory muscles of respiration (neck muscles, intercostals, pectorals, scapular muscles, and the abdominals) and cause abnormal pulmonary function (below 80% of the normal predicted FVC); and low paraplegia (injury above T12) alter trunk muscle groups as well (Schilero et al., 2014). These abnormalities result in inefficient oxygen uptake, impaired coughing, predisposition for atelectasis, pneumonia, airway hyper-responsiveness, obstructive sleep apnoea, and respiratory failure (Schilero et al., 2014). These complications are responsible for many cases of morbidity and mortality among people with SCI, especially for those with tetraplegia (Schilero et al., 2014; World Health Organization, 2013).

Changes to thermoregulation

Individuals with SCI to the cervical or high thoracic levels present reduced capacity to regulate body temperature due to injuries to T4-T6 (centre responsible for thermoregulation) with impaired vasodilatation and sudomotor control. This increases the risk of hyperthermia in warm environments or during physical activity; hypothermia in cold or ambient temperatures; and hypohidrosis below the injury, occasionally related to comorbidities (Karlsson, Krassioukov, Alexander, Donovan, & Biering-Sorensen, 2012). In the physical activity setting, caution should be exerted with cervical and high thoracic SCI cases that are more susceptible to dehydration, heat exhaustion, heat syncope, and heat stroke (Bhambhani, 2002).

Changes to the skin

The skin of a person with SCI is more vulnerable to pressure, friction and heat due to impaired sensation, immobility and deficient vasoregulation (Karlsson et al., 2012). Pressure ulcers are the most common SCI secondary complications, especially among individuals with complete paraplegia affecting their health, quality of life and function (Chiodo et al., 2007).

Pressure ulcer. According to the National Pressure Ulcer Advisory Panel, there are four stages of skin damage usually observed on areas close to the surface of the skin, such as the ischium, coccyx and heels: Stage 1) intact skin with firm consistency, presenting erythema, increased or decreased temperature, and nociception (itching or pain); Stage 2) partial thickness loss of dermis clinically described as an abrasion, blister, or superficial open ulcer; Stage 3) full thickness tissue loss with visible subcutaneous adiposity but not through underlying fascia; Stage 4) full thickness skin loss with damage to muscles, tendons, and bones. In addition there are two other stages: *Unclassified* full thickness tissue loss covered by slough or eschar, which prevents depth assessment of the wound; and *Suspected deep tissue injury* purple/maroon colouring of intact skin with abnormal consistency or sero-sanguineous filled blisters indicating extensive tissue damage (Karlsson et al., 2012; The National Pressure Ulcer Advisory Panel, 2007). Pressure ulcers progress from the deep structures, close to the bone, and finally erupt to the surface of the skin. Hence, prevention of pressure ulcers is one of the main aspects of SCI management and requires pressure relief strategies, skin checks for redness and or injuries, and healthy nutritional habits (World Health Organization, 2013). When established, pressure wounds are treated with antibiotics and skin graft surgery.

Changes to neuromuscular and connective tissue systems

Progressive structural and contractile deterioration is detected in skeletal muscles one month after denervation caused by SCI (Nash, 2005). Previous studies have indicated lower fat-free mass, higher muscle atrophy and smaller muscle fibres on paralysed limbs (Buchholz et al., 2003; Lavis et al., 2007). Diminished contractile protein, lower peak contractile forces, and inferior fatigue threshold also impose greater efforts to physical exertion (Nash, 2005). Coupled with muscle imbalances, contractions, overuse injuries of the shoulder and arm complex, spasticity, and heterotopic ossification, people with SCI are prone to serious injuries and pain to the upper and lower limbs (Nash, 2005).

Shoulder injury. Over one third of the paraplegic population and a higher proportion of the tetraplegic population have shoulder pain (Fullerton et al., 2003). Musculoskeletal injury occurs on the shoulder, elbow or wrist joints due to either increased loads during transfers and wheelchair propulsion or as a consequence of upper limb muscle denervation (Fullerton et al., 2003). Common dysfunctions are rotator cuff tears and subacromial impingement, often resulting from muscle weakness, decreased range of motion, lack of muscle endurance, poor posture, and overuse (Nash, 2005).

Spasticity (spasm). Spasticity is a sustained increase in tone caused by the hyperexcitability of the tendon/muscle stretch-reflex in response to rapid lengthening of the muscle, noxious stimulus, or increased neural system activity during physical activity (Mukherjee & Chakravarty, 2010). Uncontrolled spasm can generate pain and lead to contracture of joints, thereby restricting daily functional activities. Some degree of muscular spasm can be useful in promoting venous return, maintain tone of denervated muscles, and assist with weight bearing during transfers (Burt, 2004).

Neuropathic pain. Neuropathic pain is caused by abnormal signals from damaged nerves in the area of injury, or a mismatch between sensory and motor mappings within the cortex and is perceived at or below the level of injury and is a prevalent long-term complication (Burt, 2004; McColl et al., 2012; Wannapakhe, Arrayawichanon, Saengsuwan, & Amatachaya, 2013). It is clinically described as constant or intermittent paraesthesia or burning sensation, and is correlated to an increase in age (Burt, 2004; World Health Organization, 2013). It is a difficult complication to treat and may cause fatigue, depression, lack of motivation, inactivity and decreased levels of independence.

Heterotopic ossification. Heterotopic ossification is the presence of bone formation in soft tissue areas, caused by traumatic injuries, burns, or following invasive surgeries (Ramirez, Ramirez, Reginato, & Medici, 2014). It is believed to be an inflammatory response that also leads to chronic pain and reduced range of motion. In neurological injuries, spasticity may induce heterotopic ossification around major synovial joints, more commonly involving the hip, knees and, in people with tetraplegia, elbows and shoulder (World Health Organization, 2013). An Australian study involving 151 traumatic SCI patients identified a prevalence of 11% of heterotopic ossification and revealed associated risk factors (Reznik et al., 2014). Significant risk factors were history of DVT and/or pulmonary emboli, multiple pressure ulcers and AIS score B.

Changes to genitourinary and gastrointestinal systems

Bladder and bowel regulation arise from nerves exiting S2-S4/S5 segments of the spinal cord and are frequently impaired in the event of a SCI (McColl et al., 2012; World Health Organization, 2013). Neurogenic bladder is a common consequence and requires indwelling or intermittent catheterisation for voiding, though they also increase the risks for urinary tract infections (Burt, 2004; Nicolle, 2014). Neurogenic bowel is commonly present and usually managed by bowel motility regimes associated with medication (laxatives, suppositories, and enemas) (Burt, 2004). As for sexual function, men and women face possible impairment regarding lubrication, erection, ejaculation, and reproduction (Anderson, Borisoff, Johnson, Stiens, & Elliott, 2007; Biering-Sorensen, Hansen, & Biering-Sorensen, 2012).

Urinary tract infection (UTI). Along with bloodstream, soft tissue and wound infection, UTI is the most common infection acquired by SCI populations (D'Hondt & Everaert, 2011). Injuries between segments T6 and S2 cause loss of micturition control, involuntary bladder contraction, and striated sphincter dyssynergy; whereas injuries to neurological levels S2-S4 exhibit detrusor areflexia and sphincter dysfunction (D'Hondt & Everaert, 2011). Urological care has advanced significantly in the past few decades and renal failure and sepsis secondary to UTI are no longer the main causes of mortality among people with SCI in developed nations (Nicolle, 2014). Nonetheless, UTI remains an important cause of morbidity and treatment is challenging due to the unclear differentiation of symptomatic and asymptomatic bacteria generally present in SCI (Nicolle, 2014). Researchers have recommended the use of antibiotics to treat symptomatic cases of UTI; however, the use of antibiotics in cases of asymptomatic bacteriuria has led to reinfections due to drug malfunctioning and resistant microorganisms. Thus, asymptomatic bacteriuria should not be treated to avoid increased risk of infection and only. Maintaining low detrusor pressure and appropriate catheter care are essential for the prevention of other complications, such as hydronephrosis, sexual dysfunction, and damaged bladder and urethra (D'Hondt & Everaert, 2011).

Neurogenic bowel. Poor bowel motility causes constipation and abdominal distention, reduced lung capacity, nausea and regurgitation (Burt, 2004). These present risks to immobilised patients in cases of aspiration or may require ventilatory assistance. Fear of bowel incontinence episodes has further been reported as the main barrier to social participation among individuals with SCI (Coggrave, Norton, & Wilson-Barnett, 2009).

Sexual dysfunction. Sexual function is controlled by the autonomic nervous system and SCI often has a negative impact on the quality of life of those affected (Anderson et al., 2007). In men, erection and ejaculation are often impaired, which have led to issues with fertility and sexual satisfaction (Chehensse et al., 2013). SCI also affects women's relationships, sexual desire, arousal, and satisfaction (Cramp, Courtois, & Ditor, 2013). Concerns about incontinence during sexual activity is another significant concern for both genders (Anderson et al., 2007).

Changes to the immune system

Studies have shown that people with SCI are at a higher risk of contracting infections and it is believed that damage to the central nervous system also affects the immune system (Lalwani et al., 2014; Riegger et al., 2009; Wannapakhe et al., 2013). The central nervous system plays a significant role in the neuroendocrine integration, associated to glucocorticoid effect on immune cells and molecules (Webster, Tonelli, & Sternberg, 2002). In addition to reduced hormonal transmission, the presence of lymphocyte (immunological cells) post-SCI was remarkably low in studies involving human cells, which constitute the secondary immune deficiency syndrome (Riegger et al., 2009).

Psychosocial changes

Reduced community participation, mobility, independence, and, in some cases, impossibility of returning to pre-injury occupation and interests may lead to difficult psychosocial adjustment (Krause et al., 2004). These factors increase the risks of psychological conditions, inadequate self-care practices (e.g. improper pressure relief and wound care), risky behaviour (e.g. malnutrition, alcohol and drug abuse), and suicide. Pre-existing psychiatric disorders (e.g. personality disorder, schizophrenia, depression, and mood disorder) may even be the cause of SCI through attempted suicide (Stanford, Soden, Bartrop, Mikk, & Taylor, 2007). In both circumstances, the advent of psychological complications is influenced by subjective well-being (i.e. self-assessment of their own quality of life) and by society's attitudes towards their disability (Post & van Leeuwen, 2012; World Health Organization, 2013).

A systematic review analysed 48 studies regarding the association between psychological factors and subjective well-being among people with SCI (van Leeuwen, Kraaijeveld, Lindeman, & Post, 2012a). Results showed that negative

affective reactions, such as depression, anxiety, posttraumatic stress, and emotional distress (e.g. anger and despair) were consistently associated with lower quality of life (0.35-0.73). Most studies recorded substantially lower life satisfaction (strong effect size: -0.77 ± 0.55); higher rates of depression (between 20 and 30%), anxiety (between 13.2 and 40%), and posttraumatic stress disorder (between 7.1 and 26.6%) among people with SCI (Post & van Leeuwen, 2012).

Negative stereotyping and social attitudes (staring, ignoring, and overbearing approaches) further increase difficulties for community integration of people with SCI (World Health Organization, 2013). Those with disabilities are often discriminated and deemed incapable of working or being independent. These negative beliefs along with lack of social support increase the prevalence of psychological problems (depression, anxiety, posttraumatic stress disorder) and reduced life satisfaction among the SCI population (Post & van Leeuwen, 2012). A Norwegian study also found that children with disabilities are twice as likely to experience severe violence and three times as likely to suffer from bullying (Hanisch, 2013).

In summary, SCI is a systemic chronic condition with numerous health implications. Potential comorbidities due to motor-sensory loss and autonomic dysfunction require immediate assistance from various rehabilitation professionals and medical supplies over an extended period. Mental health issues implicate further psychological, psychiatric, and social support (Kennedy, Sherlock, & Sandu, 2009). As mentioned previously, this situation imposes great economic burden and social injustice on those affected with SCI and their families (Cao et al., 2011). Efforts from local and international governments are fundamental to guarantee the rights of people with disabilities regarding access healthcare and equal social opportunities. The following section covers advances made in the legislative and healthcare systems around the world, and specifically those that apply to Australia and New Zealand.

2.3 HUMAN RIGHTS OF INDIVIDUALS WITH DISABILITIES

People with SCI are at a disadvantage regarding health, social and economic status (World Health Organization, 2013). Throughout the past three decades, the

World Health Organisation (WHO), United Nations (UN) and local governments have improved strategies to offer people with disabilities more justice and equality.

In 1981, the WHO instated the *International Year of Disabled Persons* (Mahler, 1981). The main drivers were to increase awareness to the oppressing conditions faced by people with disabilities and promote technical cooperation between developed and developing countries. Several events supported people with disabilities to take actions within their societies, ultimately reducing disability through prevention, rehabilitation and equalisation of opportunities (Mahler, 1981). The momentum created by the *International Year of Disabled Persons* was trailed by the *World Program of Action Concerning Disabled Persons* and the *UN Decade of Disabled Persons* between 1983 and 1992. This decade had the mission to accomplish the aims set in 1981, transitioning charity programs into self-empowered organisations that drafted and implemented inclusion policies. Many goals were achieved especially in regards to global consciousness, though awareness alone was not enough to ensure equal opportunity for all (The United Nations, 1992). By the end of 1992, the UN proposed a long-term strategy that extended into the year 2000 and beyond under the theme “A Society for All: From Awareness to Action”. The main objectives were to accelerate advances made by people with disabilities in the political, cultural, social and economic spectrums (The United Nations, 1992). Recently in April 2014, the 67th World Health Assembly endorsed the *WHO global disability action plan 2014–2021: Better health for all people with disability*. Predictions believe that one billion people with disabilities will benefit from the action plan aimed at expediting WHO’s and governments’ efforts to enhance the quality of life (Sixty-Seventh World Health Assembly, 2014).

The current United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) was formulated between 2002 and 2006. It institutes the human right of people with disabilities to the highest attainable standard of health (Article 25) (The United Nations, 2006). New Zealand played an active role in facilitating of the original CRPD and Australia became part of the convention in 2008 (Australian Human Rights Commission, 2013a). As of May 2014, 130 countries (coloured in blue in **Figure 2.2**) have rectified the original CRPD and 76 states (in orange) rectified the Optional Protocol, including Australia (The United Nations, 2014). The Optional Protocol also endorses the same principals, but differs on how the *Convention* is monitored.

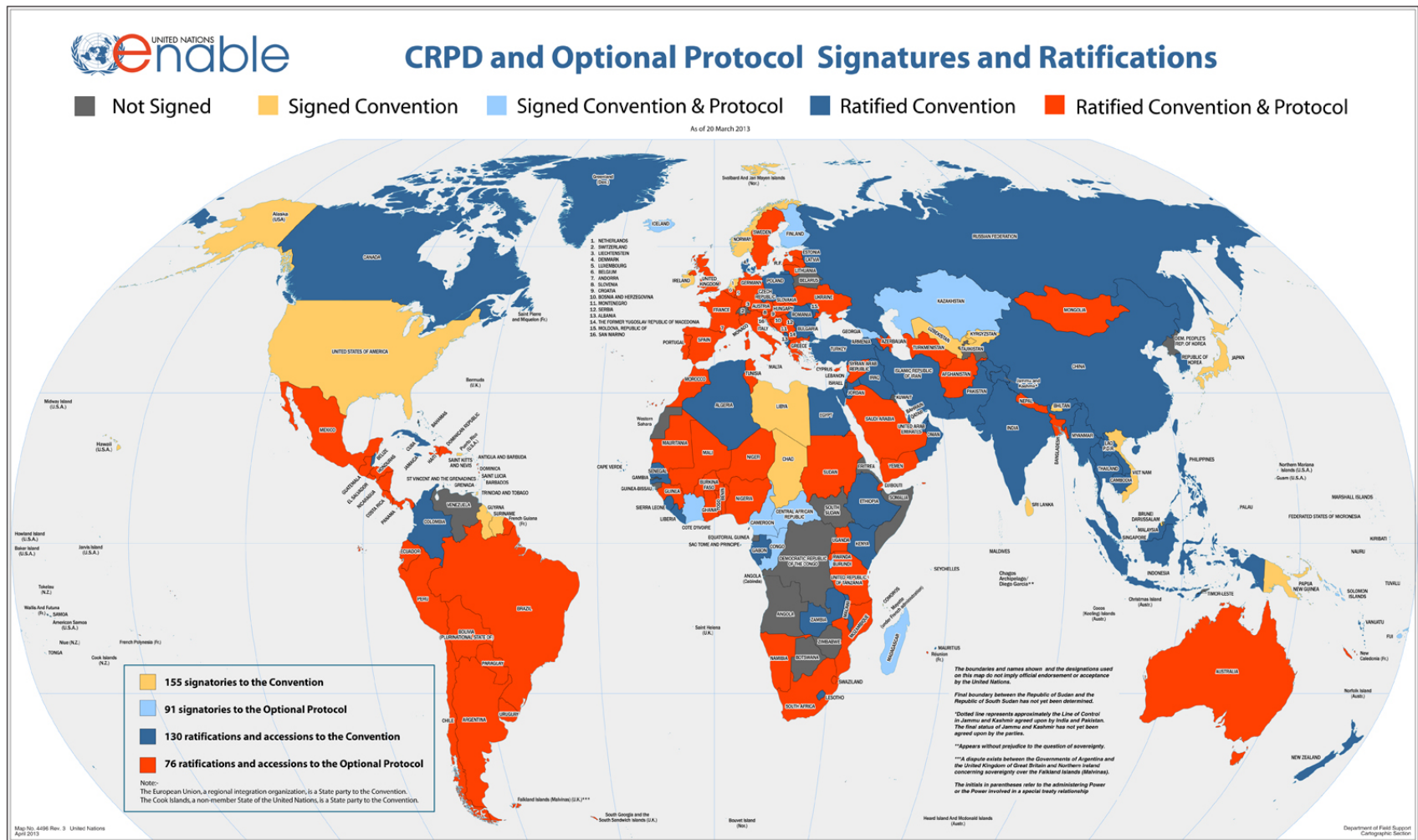


Figure 2.2. Countries that rectified the *Convention on the Rights of Persons with Disabilities* (CRPD) or the Optional Protocol. From <http://www.un.org/disabilities/documents/maps/enablemap.jpg>, by the Department of Field Support Cartographic Section, 2013, United Nations Press.

The main principals that guide the CRPD (2006) are:

“... respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity; accessibility; equality between men and women; respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities (The United Nations, 2006).”

States that ratified to the CRPD have the legal obligation to:

“...engage themselves to develop and carry out policies, laws and administrative measures for securing the rights recognized in the Convention and abolish laws, regulations, customs and practices that constitute discrimination (Article 4) (The United Nations, 2006).”

The *DisabilityCare Australia: National Disability Insurance Scheme* (National Disability Insurance Scheme) Act 2013 was instated to effectuate Australia’s commitment to the CRPD (New York, 2006) (“National Disability Insurance Scheme Act 2013,” 2013). In summary, the Act’s objectives are to provide healthcare support for people with disabilities; deliver services to improve the coordination of referral services and activities; fund participants or entities to promote economic and social inclusion; and raise community awareness of issues that affect the inclusion of people with disabilities in society. Through an insurance-based approach, individual plans are developed to support and fund each participant. People with disabilities are entitled to the NDIS if:

“...impairments are likely to be permanent... to one or more intellectual, cognitive, neurological, sensory, or physical impairments or to one or more psychiatric condition... resulting in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities: communication, social interaction, learning, mobility, self-care, capacity for social or economic participation; and the person is likely to require support under the NDIS for the person’s lifetime (“National Disability Insurance Scheme Act 2013,” 2013).”

The Australian Human Rights Commission issued a briefing about Australia and the CRPD in August 2013 and revealed deficient areas regarding full inclusion of people with disabilities in society. The Commission stated that employment rates have been stagnant since the *Disability Discrimination Act 1992* and raised

awareness of the issue. They urged the Australian Government to remove barriers in the workplace and improve access to justice (Australian Human Rights Commission, 2013j).

As for New Zealand, the government's Accident Compensation Corporation (ACC) provides comprehensive support and services to those severely injured regardless of the cause or who is accountable (Wilson, Derrett, Hansen, & Langley, 2013). The ACC assists with medical treatment, rehabilitation, technological support and earnings-related compensation, thus providing effective financial support to those injured (Wilson et al., 2013). Studies have shown positive outcomes among people with SCI supported by the no-fault compensation scheme, preventing the downward spiral of financial burden and further health complications due to lack of assistance (Paul et al., 2013).

Further community involvement and advocacy is necessary to consolidate the rights of people with disabilities (Gainforth, Latimer-Cheung, Athanasopoulos, & Martin Ginis, 2014). To be specific, rehabilitation professionals have the responsibility to deliver the best available treatment for their patients and assist patients throughout their transition into different health services. The subsequent section describes a brief history of advances in rehabilitation for SCI and current phases of therapy involved.

2.4 SPINAL CORD INJURY AND REHABILITATION

Until the 1940's, spinal cord injuries (SCIs) were considered untreatable ailments and those affected presented extremely low life expectancies (Guttmann, 1979). Sir Ludwig Guttmann was one of the first neurologists to advocate for rehabilitation and social re-integration of patients with SCI. He strongly recommended physical activity to restore fitness and independence within family, community, and work life. Guttmann became involved with the establishment of the Spinal Cord Unit at Stoke Mandeville (Aylesbury, England) and conducted numerous studies that led to drastic improvements in SCI care (Schultke, 2001). His remarkable efforts in science and society led to the foundation of the International Society of Paraplegia and the Stoke Mandeville Games, precursor of the International Paralympic Games (International Paralympic Committee, 2014).

The current SCI rehabilitation model is fundamentally influenced by Guttman's research. Immediate intervention, concern to both physical and psychological aspects of rehabilitation, and assistance on their return to society underpin the success of most interventions (Riddoch, 1941). Health-care systems around the world offer different levels of support according to the countries' economy and social justice. An individual's experience during rehabilitation is a good indicator of the countries' health system, for a person with SCI utilises practically all stages of services from emergency care to community reintegration (Burt, 2004). According to the WHO (Australian Human Rights Commission), individuals that suffer SCI require specialised health assistance in three important phases: 1) acute care, 2) inpatient rehabilitation, and 3) health maintenance (World Health Organization, 2013).

2.4.1 Acute care

A systematic review on pre-hospital care considered this phase crucial to minimise the risk of secondary injury to the spinal cord and comorbidities, such as pressure ulcers (Ahn et al., 2011). Recommendations included stabilisation of vital signs; head and spinal immobilisation with a cervical collar and padded spinal boards to reduce pressure on the occipital and sacral regions; air-way management with intubation if necessary; and transportation of traumatic SCI to a definite hospital within the first 24 hours of injury. Immediate assessments for neurological and orthopaedic complications are required to address life-threatening situations on the way to and at hospital centres. Surgeries may be necessary to decompress the spinal cord and/or stabilise the spinal column (World Health Organization, 2013). Conservative management is an option for some, involving immobilisation combined with spinal traction with the use of orthoses. Acute care of non-traumatic SCI is disease specific and may implicate medical or surgical intervention.

Patients are maintained under surveillance to prevent UTI, DVT, pulmonary complications, loss of mobility and strength, as well as pain management (Bragge et al., 2012; Wuermsler et al., 2007). Common clinical presentations in acute SCI are autonomic dysreflexia, spinal shock (loss of spinal cord activity and reflexes), and neurogenic shock (hypotension) (Wuermsler et al., 2007). Physiatrists /physicians play an important role during this phase. They ascertain appropriate acute care practices and long-term care strategies, including use of suitable orthoses, bladder management and bowel programming (Wuermsler et al., 2007).

2.4.2 Inpatient rehabilitation

SCI inpatients and families warrant multi-disciplinary assistance to re-establish quality of life and independence, as well as guidance on the prevention of secondary complications (Gomara-Toldra, Sliwinski, & Dijkers, 2014). In the physical realm of rehabilitation, physiotherapists and occupational therapists work collaboratively to prepare patients with SCI for life in the community. Traditionally, the physical rehabilitation phase is guided by the predicted functional outcome of each individual with SCI (Behrman & Harkema, 2007). This recovery period varies from weeks to years depending on the patient's neurological status, presence of comorbidities, age, weight and motivational factors (Chu et al., 2012). Prolonged length of stay in the hospital setting has been frequently attributed to medical factors (e.g. pain, fatigue, spasticity, etc.) and behavioural issues (i.e. uncooperative to treatment and need for psychosocial assistance) (Dijkers & Zanca, 2013). Aside from ample psychological support, the basis of most therapies are functional everyday activities such as bladder and bowel management, pressure relief, bed mobility, transfers, use of assistive devices, wheelchair skills and/or gait training (Taylor-Schroeder et al., 2011).

Specialised care on activities of daily living is provided by occupational therapists, responsible for re-educating patients with SCI to perform self-care routines (Ozelie et al., 2012). Sessions commonly entail assessment, personal hygiene (dressing, grooming, toileting, and dressing) adaptation, eating strategies, range of motion/lengthening exercises, sensorial training (fine motor activities, vestibular/visual/perceptual/ training, cognitive retraining, desensitization, etc.), home management, and community activities among others. Improved functional outcomes and social participation have been associated with increased engagement in occupational therapy treatment (Ozelie et al., 2012).

Physiotherapy assistance is also crucial during the initial stages of SCI. Professionals of this field assess, diagnose, and assist the treatment and prevention of diseases and disabilities through movement and functional skills (Australian Physiotherapy Association, 2014; Teeter et al., 2012). A multicentre study in the United States (Taylor-Schroeder et al., 2011) analysed the most common components of inpatient physiotherapy according to the SCI classification: high tetraplegia received range of motion/lengthening, strengthening and transferring exercise; people with low tetraplegia focused on transfers and strength; paraplegic individuals emphasised transferring activities, followed by range of motion/lengthening, and strengthening; and patients with AIS D practiced gait and

balancing skills, as well as strengthening. Increased time dedicated to physiotherapy was directly correlated to improved functional independence, participation in society, quality of life, and prevention of comorbidities (Taylor-Schroeder et al., 2011).

Another group of Dutch researchers revealed that over 90% of treatments delivered in three different rehabilitation centres consisted again of mobility (strengthening, wheelchair propulsion and gait training) and self-care interventions (van Langeveld et al., 2011). Recent studies on rehabilitation have shifted the focus from training compensatory strategies towards whole body activity-dependent exercises and, ultimately, research into a cure for SCI (Behrman & Harkema, 2007; Galea, 2012). Thus, physical health and fitness have been reinforced to sustain conditions for full recovery in the advent of a cure for SCI.

2.4.3 Health maintenance

Although Australia and New Zealand's general population are internationally well ranked in life expectancy, modern life-style diseases (e.g. obesity and inactivity) represent a threat to all and especially to those with disabilities (Buchner et al., 2008; World Health Organization). Following discharge from rehabilitation services, people with SCI require continuous health monitoring to ensure appropriate care and prevention of aforementioned secondary complications. Long-term health can be maintained via regular check-ups for adequate physiological functioning; education in controlling of risk factors such as weight management, healthy diet, and prevention of overuse injuries. These can be achieved through physical activity engagement and community participation (World Health Organization, 2013).

The following section encompasses evidence-based benefits of physical activity and its impact on physical capacity, muscular strength, body composition, functional activities, and psychosocial elements such as quality of life, self-esteem, and community participation.

2.5 SPINAL CORD INJURY AND BENEFITS OF PHYSICAL ACTIVITY

In this thesis, the types of physical activity investigated are those undertaken during free time, namely, leisure time physical activity (LTPA) (Martin Ginis et al., 2010e). Examples of these activities are wheeling, playing sports, or exercising at a gym, other than their daily activities that involve manual wheelchair use for mobility,

occupational activity, or incidental activity (e.g. postural relief of pressure points). Physical activity is one of the main agents for muscle strengthening, physical capacity (peak power output [PO_{peak}] and oxygen uptake [VO_{2peak}]), and for the development of alternative mobility skills to aid the paralysed portion of the body (Behrman & Harkema, 2007; Hicks et al., 2011; Valent, Dallmeijer, Han, Talsma, & van der Woude, 2007). Mild to heavy intensity levels of training are also significantly correlated to fewer secondary complications and many psychosocial improvements (Tawashy, Eng, Lin, Tang, & Hung, 2009).

2.5.1 Physical benefits

Two extensive systematic review studies regarding the effects of physical activity detected 25 studies focused on upper body training (Valent et al., 2007) and the other comprised 69 articles involving subjects with chronic SCI (Hicks et al., 2011). Fifteen publications were duplicates and the majority were levels 4 and 5 evidence studies on a scale of 10, according to the Physiotherapy Evidence Database (PEDro) tool (Physiotherapy Evidence Database, 1999), or achieved an average of 8.8 on the 19-item list of van Tulder, Assendelft, Koes, and Bouter et al. (1997). These two classifications indicate low internal validity of studies, deterring meta-analysis (Valent et al., 2007). This is understandable due to the complex nature of studies involving SCI populations subjected to various barriers for physical activity participation (Kehn & Kroll, 2009; Martin Ginis & Hicks, 2005; Nary, Froehlich-Grobe, & Aaronson, 2011; Vissers et al., 2008). Recent level 2 studies (randomised controlled trials) (National Health and Medical Research Council, 2000) have corroborated benefits listed in previous research and have started to shift from the laboratory setting to community-based interventions (Froehlich-Grobe et al., 2014; Wise et al., 2009).

Evidence on the benefits of physical activity for muscular strength and physical capacity in people with SCI is substantial. Valent et al. (2007) identified an average increase of $17.6\% \pm 11.2\%$ in VO_{2peak} and $26.1\% \pm 15.6\%$ in PO_{peak} reported by, respectively, 13 and 12 acceptable quality studies. Hicks et al. (2011) identified 30 studies reporting improved VO_{2peak} and 16 on increased PO_{peak} in response to 4-12 weeks of moderate-intensity arm ergometry, resistance exercises, and circuit training. Inconclusive results were obtained concerning body composition changes and functionality improvements, requiring further investigation. Although the design of most studies mentioned was not optimal, the positive effects of physical activity

for strength and cardiorespiratory capacity among people with SCI are also supported by level 1 and 2 evidence studies, according to the NHMRC classification (Carvalho de Abreu, Cliquet, Rondina, & Cendes, 2009; Ditor et al., 2003; Field-Fote, Lindley, & Sherman, 2005; Froehlich-Grobe et al., 2014; Hicks et al., 2003; National Health and Medical Research Council, 2000; Wise et al., 2009).

In the past decade, randomised control trials (RCT) reinforced the evidence of benefits of physical activity participation in a variety of settings (Ditor et al., 2003; Froehlich-Grobe et al., 2014; Hicks et al., 2003; Wise et al., 2009). Researchers from McMaster University (Canada), responsible for a considerable amount of current evidence on the subject, compared the effects of an endurance and resistance training protocol in laboratory against theoretical education sessions (Ditor et al., 2003; Hicks et al., 2003). Over nine months, their SCI exercise group presented significant improvements related to power output and strength of upper limbs, perceived functional satisfaction, and reduced pain ($P < .05$) (Hicks et al., 2003). Follow-up at three months post-intervention revealed a drop in adherence from 81% to 42.7%, as well as increased pain ($P = 0.07$) (Ditor et al., 2003). Additional rigorous research testing functional electrical stimulation (FES) of weak/paralysed muscles and locomotor training presented significant increases in quadriceps cross-sectional area (Carvalho de Abreu et al., 2009) and walking speed (Field-Fote et al., 2005). FES and Body Weight Support Locomotor Training is studied in-depth by another project under SCIPA, namely *SCIPA Full-On* (Galea et al., 2013). The focus of this thesis is on physical activity viable in the community setting, such as pilot studies conducted by Wise et al. (2009), Block, Vanner, Keys, Rimmer, and Skeels (2010), and Froehlich-Grobe et al. (2014).

Home-based physical activity programs were proposed to encourage training under feasible and sustainable conditions for neurological patients and/or wheelchair users (approximately 46% diagnosed with SCI) (Block et al., 2010; Froehlich-Grobe et al., 2014), and exclusively for people with SCI (Wise et al., 2009). The logistics entailed reduction of costs and time travelled to institutions (i.e. rehabilitation or laboratory facilities). Interventions consisted of education in physiology and benefits of physical activity, exercise equipment, logbooks to enter work-outs, and professional assistance for goal setting, regular re-assessments, and self-efficacy and self-management strategies. Among the control groups, Wise et al. (2009) reinforced solely audio-visual guidance, whereas Froehlich-Grobe et al. (2014) provided self-guided educational material, resistance bands, logbooks and limited staff phone calls. After a three month intervention period, Wise et al. (2009)

observed significant increase in upper limb muscle strength, range of motion, and self-reported time engaged in physical activity in both groups, though between group differences were not relevant. Baseline time of involvement in physical activity increased from 36.3 SD \pm 48.4 per week to 127.4 SD \pm 126.5 after intervention ($P < .01$). Throughout a 12 month training period, the only significant difference between groups in Froehlich et al.'s (2014) study was related to greater exercise time invested by the intervention group (approximately 17 minutes longer per week). Nevertheless, both groups also presented significant increase in physical capacity and strength overtime. A summary of the aforementioned studies and outcomes are displayed in **Table 2.1**.

In addition to aerobic and strength improvements, physical activity is one of the main agents on the prevention of cardiovascular and secondary complications (Franklin, Durstine, Roberts, & Barnard, 2014). Along with a healthy diet and smoking cessation, exercise reduces risk factors for coronary heart disease and pre-diabetes, presenting similar effects as cardio-protective medications after acute myocardial infarction (Naci & Ioannidis, 2013). In the SCI population, CVD is reduced by long-term moderate to vigorous training, resulting in increased levels of high-density lipoproteins (HDL); as well as decreased concentrations of low-density lipoproteins (LDL), triglycerides, and glucose levels (Cowan & Nash, 2010). HDL is believed to transport excess cholesterol to the liver for excretion and functions as an antioxidant, anti-inflammatory and anti-atherogenesis agent (Alwaili, Awan, Alshahrani, & Genest, 2010). Reduced quantities of LDL, triglycerides and serum insulin cause less atherosclerotic plaque formation (Lavis et al., 2007). Physical activity has shown to decrease the onset of obesity, type II diabetes, musculoskeletal injuries, and osteoporosis (Lavis et al., 2007; Thompson et al., 2003). The underlying mechanisms for such benefits are attributed to more energy expenditure, improved glucose metabolism, higher fitness, and increased bone mineral density in response to physical activity (Astorino, Harness, & Witzke, 2013; Thompson et al., 2003).

Table 2.1. Experimental studies in the past 10 years examining the effects of physical activity on people with SCI.

Study & subjects	Intervention	Outcome measures	Results
<p>Hicks et al. (2003)</p> <p>RCT 23 males and females with SCI C4-L1, ASIA A-D Exercise group (n=11) Control group (n=12) Aged 19-65 years</p>	<p>9 months, 2x/week, 90-120 min/day</p> <p>Exercise group: Warm-up, arm ergometry, and resistance training in the laboratory setting.</p> <p>Control group: bi-monthly education session on exercise physiology and osteoporosis after SCI and relaxation techniques.</p>	<p>One repetition maximum (1RM), the discontinuous University of Toronto Arm Crank Protocol, PSS (Perceived Stress Scale), The Centre for Epidemiological Studies Depression Scale (CES-D), 9-item body satisfaction questionnaire, Short-Form 36-Item Health Survey (SF-36), Perceived Quality of Life Scale (PQOL).</p>	<p>Post-intervention: Exercise group: increased submaximal arm ergometry power output (81%; $P<0.05$), upper body muscle strength (19-34%; $P<0.05$). Reduced pain, stress and depression; presented higher satisfaction with physical function, level of perceived health and QOL ($P<0.05$) compared to Control group.</p>
<p>Ditor et al.(2003)</p> <p>RCT N=7, 5 male/2 female with SCI C5–T12, ASIA A–D Aged 42.3±3.6 years</p>	<p>9 months, 2x/week, 90-120 min/day</p> <p>Warm-up, arm ergometry, and resistance training in the laboratory setting.</p>	<p>Exercise adherence rates, PQOL, SF-36, PSS.</p>	<p>Immediately after intervention: 80.6% adherence; increased quality of life (QOL), and less pain and stress ($P<0.05$).</p> <p>3month follow-up: decreased adherence (42.7%, $P<0.01$), perceived QOL ($P<0.05$), and increased pain ($P=0.07$) and stress ($P=0.12$); negative correlation between pain and adherence ($r=0.91$, $P<0.01$).</p>
<p>Wise et al. (2009)</p> <p>RCT N=21, 11 male/10 female with SCI C1-below T5 Basic intervention group (BIG, n=11) Enhanced intervention group (EIG, n=10) Aged 43.6±14.2 years</p>	<p>3 months of home physical activity programs</p> <p>BIG: brochure and DVD/videotape on benefits of physical activity and examples.</p> <p>EIG: same as BIG with the addition of individualised instruction and exercise equipment.</p>	<p>Range of motion (ROM) measures, manual muscle testing (MMT), recording of number of days, minutes, and types of physical activity for one full week/month for 3 months.</p>	<p>BIG and EIG increased MMT/ROM scores and physical activity time at 3 months post intervention ($P<0.05$) compared to baseline; no statistical differences between groups.</p>
<p>Block et al. (2010)</p> <p><i>Project Shake-It-Up</i></p> <p>Mixed Methods: quasi-experimental study and thematic analysis. N=35 people with neurological impairment (45.7% SCI, 34.2% MS) Wait-list control group.(n=9) Intervention group (n=13)</p>	<p>10 full day sessions 2x/month</p> <p>Organised physical or recreational group activities: wheelchair sports, strength and aerobic training in the community (parks, public libraries, university campuses); educational information and skills training on independent living, capacity building and health promotion seminars.</p>	<p>General Perceived Self-Efficacy Scale (Svaasand & Ellingsen, 1983); Independent Living Assessments (ILA); personal activity logs (PAL); interviews on goals, barriers, and intervention</p>	<p>Intervention group: increased self-efficacy ($P=0.007$) compared to control and differences were maintained at 12 months follow-up. ↑ Independent living skills, confidence in abilities in education, employment, housing, transportation, accessibility, physical activity participation, and health promotion.</p>

Study & subjects	Intervention	Outcome measures	Results
<p data-bbox="181 333 479 354">Froehlich-Grobe et al. (2014)</p> <p data-bbox="181 384 450 405"><i>Project Workout on Wheels</i></p> <p data-bbox="181 435 618 576"> RCT N= 128 wheelchair users (46.1% SCI, 20.3% CP, 7.8% MS, 7.8% others) Staff supported group (n=69) Self-guided group (n=59) Aged 44.5±12.5 years </p>	<p data-bbox="660 333 1005 354">12 month, home-based exercise trial</p> <p data-bbox="660 384 1099 453">Self-guided: educational materials, staff phone calls, resistance bands, self-monitored exercise (study logs).</p> <p data-bbox="660 483 1099 624">Staff-supported: similar intervention as the Self-guided group; educational workshop to increase knowledge and behavioural capabilities to exercise; goal setting; intervention phone calls; relapse prevention; and newsletters.</p>	<p data-bbox="1133 333 1570 402">Self-reported exercise logs, 1RM, accelerometer, graded discontinuous arm crank test.</p> <p data-bbox="1133 432 1570 624">The Participation Survey, Lee Fatigue Scale (LFS), Bodily Pain Subscale (SF-36), CES-D, Quality of Life Index (QLI), Felt Energy and Emotion in Life (I FEEL), Behavioural Risk Factor Surveillance Survey, Barriers to Health Activities among Disabled Persons (BHADP), Self-Rated Abilities for Health Practices Scale (SRAHP).</p>	<p data-bbox="1606 333 2051 402">Self-reported exercise minutes were moderately correlated to accelerometer data ($P < .01$).</p> <p data-bbox="1606 432 2051 576">Staff-supported group reported significantly greater exercise time (~ 17min/week) ($t = 10.6$, $P = .001$); non-significant differences in aerobic capacity ($t = .76$, $P = .45$) and strength ($t = 1.5$, $P = .14$) compared to Self-guided group.</p> <p data-bbox="1606 606 2051 697">Only exercise barriers and exercise (for staff-supported) and self-efficacy (for self-guided) predicted weekly minutes of aerobic exercise over 12 months.</p>

Excessive physical activity increases the risks of musculoskeletal injuries, autonomic or thermal dysregulation, skin burn, or sudden cardiac death and myocardial infarction in presence of a serious congenital or acquired cardiovascular condition (Nash, 2005; Thompson et al., 2003). A systematic review on adverse events in the SCI population did not encounter evidence of cardiovascular complications in the course of training in 38 studies (Warms et al., 2013). Nevertheless, these studies complied with safety precautions and physical activity guidelines. Provisions that minimised the risk of injuries involved: caution with individuals with severe spasm; attention for inflammatory signs in lower extremities; maintenance of adequate range of motion, muscle strength and balance; bowel and bladder preparation before exercising; use of appropriate equipment; exercising in mild temperatures; constant hydration; cessation of activities in cases of autonomic dysreflexia and heat stress; and lastly with the inclusion a cool-down period to avoid hypotension (Nash, 2005). To ensure safety, pre-screening for underlying medical conditions, high predisposition for autonomic dysreflexia, current injuries and fitness levels are necessary before engaging in physical activity (Martin Ginis et al., 2011a).

Physical activity levels are measured via direct or self-reported measures. The objective reference standard uses the doubly labelled water technique, a costly procedure that measures calorimetry in the general and SCI population (Prince et al., 2008; Tanhoffer, Tanhoffer, Raymond, Hills, & Davis, 2012). Other options of direct assessments involve heart rate monitors, accelerometers, SenseWear Armband, motion sensors and physiologic markers. These methods presented a weak association with the doubly labelled water technique (R^2 ranged between 0.13 and 0.30, $P > 0.05$) (Tanhoffer et al., 2012). Subjective measures, such as the *Physical Activity Scale for Individuals with Disability (PASIPD)* and the *Physical Activity Recall Assessment (PARA-SCI)* were proposed as low-cost alternatives to detect changes in LTPA in individuals with disabilities.

PASIPD was weakly correlated to the doubly labelled water reference standard, though PARA-SCI obtained the best estimate for physical activity energy expenditure compared to all objective and subjective tools assessed ($R^2 = 0.62$, $P < 0.05$) (Tanhoffer et al., 2012). PARA-SCI also presented strong convergent validity, being significantly correlated to muscle strength (1 repetition maximum, $r > 0.21$, $P < .05$), and aerobic fitness (VO_{2peak} , $r > 0.26$, $P < .04$) (Latimer, Martin Ginis, Craven, & Hicks, 2006j). PARA-SCI is the only validated and reliable measure developed specifically for the SCI population and therefore would be well suited to studies of physical activity of people living in the community with SCI (Latimer et al., 2006j).

Utilising PARA-SCI, a sample of 347 individuals in Canada registered an average of 25.49 ± 41.11 minutes of moderate and 19.14 ± 37.77 minutes of heavy intensity LTPA per day (Martin Ginis et al., 2010a).

2.5.2 Psychosocial benefits

In addition to somatic improvements, physical activity is frequently associated with psychological benefits. Among the improvements are increased quality of life and social participation, as well as reduced stress/anxiety and depression rates. Quality of life is a self-evaluation of one's well-being regarding cognitive (judgements) and affective (moods and emotions) satisfaction (van Leeuwen et al., 2012a). A systematic review involving 48 studies on people with SCI correlated quality of life to: perceived purpose in life (0.50-0.71), control over life (0.49-0.69), comprehension and management of their situation (0.32-0.76), self-esteem (0.33-0.73), positive affective emotions (joy, excitement, and vigour) (0.42-0.52), hope (0.27-0.64), and self-efficacy (0.23-0.62) (van Leeuwen et al., 2012a). Several cross-sectional studies and a few experimental designs assessed the impact of physical activity on various psychological domains of people with SCI.

In a randomised control trial mentioned previously, significant improvements were obtained in measures of quality of life and reduced pain, stress, and depression ($P < .05$) in the SCI exercise group compared to control (Hicks et al., 2003). Conversely, 3 months after the intervention period ceased, participants showed lower quality of life scores ($P < .05$), and increased pain ($P = 0.07$) and stress ($P = 0.12$) (Ditor et al., 2003). These results highlight the impact exercise exerts on mental health. In fact, a survey involving 277 individuals with SCI identified physical activity as the main factor influencing quality of life (Anneken, Hanssen-Doose, Hirschfeld, Scheuer, & Thietje, 2010). As shown on **Table 2.2**, studies have shown significant advantages for active individuals with SCI on many aspects of psychological health: energy, self-confidence, social engagement (e.g. higher employment rates and extroversion) (Anneken et al., 2010; Gioia et al., 2006; Krause et al., 2004), and self-efficacy; along with reduced fatigue, pain, anxiety, and depression (Gioia et al., 2006; Tawashy et al., 2009).

Interestingly, studies involving SCI and physical activity did not report on self-esteem outcomes, though it has a profound role on the development of personality, ability to function, and affective behaviours (Tzonichaki & Kleftaras, 2002). Evidence also suggests that self-esteem is a multidimensional construct that requires

evaluation of specific facets of a person (Robins, Hendin, & Trzesniewski, 2001). Only one cross-sectional study focused on its strong association with recreational activities for the SCI population (Coyle, Lesnik-Emas, & Kinney, 1994). Coyle et al. (1994) used the *Rosenberg Self-Esteem Scale* (RSS), which shows strong reliability, internal consistency, and convergent validity in different populations, and is the most widely used self-reported scale (Coyle et al., 1994; Gray-Little, Williams, & Hancock, 1997; Robins et al., 2001). The scale has strong coefficients of reproducibility, scalability, and reliability (respectively .92, .72, and .85) and is the most widely used self-esteem measure among researchers (Coyle et al., 1994; Gray-Little et al., 1997; Robins et al., 2001; Rosenberg, 1979). Other self-esteem measures, such as *The Single Item Self-esteem Scale* and components of the *Global Self-Esteem Scale* have shown high construct validity, but lower reliability compared to the RSS (Robins et al., 2001). Thus, studies suggest that the RSS would be a more adequate measure of self-esteem in people with SCI to reveal more information concerning this attribute.

Table 2.2. Studies associating physical activity and psychosocial health in people with SCI.

Study subjects	Research Design	Outcome measures	Results
Krause et al. (2004) N=5947	Cohort study	Craig Handicap Assessment and Reporting Technique, Social Security Death Index	Lower raising the odds of dying by 26% for physical independence, 31% for social integration, 38% for occupation, and 39% for mobility.
Gioia et al. (2006) N=137 chronic SCI	Cross-sectional study comparing people classified as high frequency vs no sports participation	The State-Trait Anxiety Inventory, Form X2 (STAI-X2), the Eysenck Personality Questionnaire for extraversion (EPQR) and the questionnaire for depression (QD)	High frequency presented less anxiety, depression, and were more extroverted ($P<.05$). Reduced anxiety was highly association with sports ($R^2 = .0404$, $P<.01$)
Tawashy et al. (2009) N=49 chronic SCI	Prospective cross-sectional design analysing the impact of different levels of physical activity	PARA-SCI, Fatigue Severity Scale, CESD-10 Instrumental Support Evaluation List (ISEL), Stanford Self-efficacy for Managing Chronic Disease scale (ESE)	Activity reduced fatigue ($P=.001$), and pain ($P=.015$); higher levels of self-efficacy ($P=.008$). More total physical activity was related to higher self-efficacy ($P=.045$) and less depression ($P=.026$).
Anneken et al (2010) N=277 chronic SCI	Cross-sectional survey comparing active and inactive individuals	QoL-Feedback from Hanssen-Doose and Schule	Active: ↑employment ($P=0.007$), were previously active ($P=0.007$), had better wheelchair mobility, had a higher social QoL ($P<.05$), more 'leisure time' ($P=0.003$), 'physical capacity', 'energy' and 'self-confidence' ($P<0.001$).

Increased community engagement of people with SCI is another fundamental facet of quality of life. Over 50 studies on the subject were included in a systematic review conducted by Müller, Peter, Cieza, and Geyh (2012). Social support was associated with improved life satisfaction, lower depression rates, less negative affective feelings (e.g. helplessness, pessimism, loneliness) and reduced suicidal thoughts. Participation in sports or physical activity programs has shown to facilitate community integration, resulting in improved psychosocial health (Anneken et al., 2010; Gioia et al., 2006; Krause et al., 2004). Physical activity has also been inferred as a mediator for identity reconstruction of those affected with SCI (Levins, Redenbach, & Dyck, 2004). Furthermore, mortality odds have shown to decrease by 31% with social integration, 38% with occupation, and 39% with mobility (Krause et al., 2004).

As verified, quality of life and community involvement are vital for people with SCI. However, these two components have not been effectively delivered together in one physical activity initiative for the SCI public. In order to address this gap, the SCIPA Com program was developed according to the best guidelines available in literature (Jacobs & Nash, 2004; Martin Ginis et al., 2011a; Myslinski, 2005). The psychological outcomes of the SCIPA Com enterprise were also periodically assessed using surveys with multidimensional constructs of one's life, serving as success indicators of the intervention (Anneken et al., 2010; Hill, Noonan, Sakakibara, & Miller, 2010). The *World Health Organization Quality of Life–BREF (WHOQOL-BREF)* scale was preferred over 13 quality of life instruments in a systematic review that identified it as the most comprehensive and efficient quality of life instrument currently available (Hill et al., 2010). Though other tools presented promising results (i.e. *Sickness Impact Profile, Quality of Life Profile for Adults with Physical Disabilities, Short Form-36V, and Sense of Well-being Index*), the WHOQOL-BREF has been well validated in a wide array of the global population, including people with SCI (Jang, Hsieh, Wang, & Wu, 2004).

The WHOQOL-BREF is a self-reported questionnaire identified as the best available tool to measure both objective and subjective aspects of quality of life in SCI populations (Hill et al., 2010). The WHOQOL-BREF has shown a very strong positive correlation (0.89) with the WHOQOL-100 domain scores (criterion validity), good to excellent internal consistency ($\alpha = .75 - .87$), item-domain validity ($r = 0.41 - 0.77$), and capacity to differentiate sub-groups such as level of SCI with moderate to high reliability ($\alpha = .74 - .87$) (Hill et al., 2010; Lin, Hwang, Chen, & Chiu, 2007).

As for physical activity recommendation and training, guidelines have been developed to provide clear information on the types of activities available, frequency, and intensity of training to help health professionals and consumers promote physical activity (American College of Sports Medicine, Durstine, G., Painter, & S., 2009; Martin Ginis et al., 2011a; Myslinski, 2005). The following section expands on the current evidence reported in SCI literature for a physically active life-style that underpins intervention studies.

2.5.3 Physical activity guidelines for people with SCI

Recent studies have proposed guidelines to provide adequate information on physical activity participation among the SCI population (American College of Sports Medicine et al., 2009; Buchner et al., 2008; Jacobs & Nash, 2004; Martin Ginis et al., 2011a; Myslinski, 2005), as well as engagement strategies to ensure long-term adherence to physical activity have been proposed (Brawley et al., 2013; Latimer, Martin Ginis, & Arbour, 2006a). These studies provide the basis of intervention programs to promote physical activity participation.

A careful methodological approach included the input of a multidisciplinary expert panel comprising people with SCI, rehabilitation specialists, qualified exercise professionals, physicians and researchers (Martin Ginis et al., 2011a). Panel members analysed a systematic review of 69 publications on the subject mentioned previously (Hicks et al., 2011). They concluded that aerobic and resistance training presented sufficient evidence to promote improvements in physical capacity and muscle strength in people with chronic SCI. Time-efficiency of training programs was also debated to ensure long-term adherence by participants. Other studies on physical activity training and their principals for exercise prescription were considered as well (American College of Sports Medicine et al., 2009; Jacobs & Nash, 2004; Myslinski, 2005). Under the *Adults with Disabilities* section, the 2008 Physical Activity Guidelines for Americans emphasised the importance of consulting with health-care providers for the safe execution of adapted physical activity (i.e. “*adaptations that could facilitate physical activity across a wide range of individual differences*”) (Steadward, Watkinson, & Wheeler, 2003). Based on the evidence provided by these studies, recommendations relevant for community-based physical activity programs are as follows:

Frequency. Two days per week of aerobic and strength training.

Intensity and duration of aerobic training. Moderate-to-heavy intensity activity for a minimum of 20 min (with progressive increment), in uninterrupted episodes of at least 10 min (or as much as their condition allows).

Intensity of strength training. 70-80% of 1 repetition maximum (i.e. 8-10 repetitions of each exercise for each major muscle group); and gradual increment up to 3 sets of 8-to-10 repetitions. For wheelchair users, importance was given to strengthening posterior shoulder and upper back muscles.

Types of activities. Resistance training (with the use of free weights, elastic tubing and bands, and weight machines), arm-ergometry, a combination of both, or circuit resistance training (Jacobs & Nash, 2004; Martin Ginis et al., 2011a; Sasso & Backus, 2013); treadmill walking, cycling, swimming, wheelchair ergometry (Martin Ginis et al., 2011a); Pilates, yoga, gardening, balance exercises, or sports participation (e.g. hand cycling, wheelchair basketball, sailing, and kayaking) in combination with fitness training in community fitness centres were also considered in the program.

Safety procedures. Training with supervision from a qualified exercise professional (Buchner et al., 2008); gradual increment of repetitions, sets, and duration of exercises; ensuring a hazard free environment and adequate room temperature; monitoring of sign and symptom of autonomic dysreflexia, orthostatic hypotension, skin lesions, and core temperature; checking if participants took necessary precautions with bowel and bladder management before training, hydration, and suitable clothing for training (Arbour-Nicitopoulos et al., 2013; Jacobs & Nash, 2004).

Goal-based physical activity program. Participants are required to establish specific, measurable, attainable, realistic, and time specific (SMART) goals to guide the development of their physical activity program (Bovend'Eerd, Botell, & Wade, 2009). Specificity accounts for the participant's neurological level of injury, physical abilities, and especially their needs (Myslinski, 2005). These

goals should be consulted with rehabilitation experts to establish realistic expectations of physical improvements within three month periods. *The Patient Specific Functional Scale (PSFS)* is a valid, reliable, responsive, and efficient instrument that can be used to detect self-perceived changes in goals overtime on individualised outcomes (Horn et al., 2012).

The use of the PSFS is recommended by reputable organisations, including the American Physical Therapy Association, Physiotherapy New Zealand, and New Zealand's national no-fault accident and injury insurer (Accident Compensation Corporation (ACC), 2008; Horn et al., 2012). Developed in 1995 by Stratford et al., the PSFS assesses functional changes through a self-reported/patient-specific measure applicable to a variety of conditions or disabilities (Horn et al., 2012; Stratford, Gill, Westaway, & Binkley, 1995). Studies analysing the *International Classification of Functioning, Disability, and Health (ICF)* support the content validity of the PSFS especially in the activity (80%) and participation (7.7%) components (Fairbairn et al., 2012). In subjects with chronic low back pain, the PSFS presented moderate to excellent correlation with the *Roland-Morris Questionnaire* ($r = 0.55$ to 0.74 , $P < .001$), strong test-retest reliability (ICC = 0.97), and high sensitivity of changes overtime ($P < .001/.006$) (Stratford et al., 1995). In the activity component, PSFS also had similar psychometric properties (construct validity is $P < .001$; ICC = 0.713; AUC = 0.887) to the *Upper Extremity Functional Index* (construct validity, $P < .001$; ICC = 0.848; AUC = 0.877), though having the advantage of being more time-efficient (Hefford, Abbott, Arnold, & Baxter, 2012).

Aside from upper limb function and low back pain, a systematic review including 66 studies confirmed the validity, reliability and responsiveness of the PSFS in other musculoskeletal conditions (Horn et al., 2012). Horn et al. (2012) revealed excellent reliability for the use of PSFS on cervical dysfunction (ICC = 0.92), and good reliability on cervical radiculopathy (ICC = 0.82). Its reliability figures were higher than those obtained by other questionnaires (e.g. the *Functional Rating Index*, global perceived effect, and the *Neck Disability Index*). One study obtained better test-retest reliability with the *Modified Oswestry Disability Index* (ICC = 0.836, 0.632 - 0.932) compared to the PSFS (ICC = 0.590, 0.226 - 0.813) in spinal stenosis patients (Cleland, Whitman, Houser, Wainner, & Childs, 2012). The *Modified Oswestry Disability Index* is mainly used on low back pain patients whereas the PSFS has been used in a diverse range of pathologies. The use of this instrument in neurological conditions warrants further investigation (Horn et al., 2012) and, given

that people with SCI present a wide variety of limitations, the PSFS is considered appropriate to measure goal-based functionality in response to physical activity.

In addition to assessing functionality, the PSFS helps establish short and long-term goals, which has proven to be an efficient strategy to increase physical activity engagement (Arbour-Nicitopoulos et al., 2013; Ditor et al., 2003). The next section analyses the importance of goal-setting and community participation in increasing physical activity levels and discourses on recently proposed adherence models.

2.6 ADHERENCE TO PHYSICAL ACTIVITY

In order to support intrinsic motivation, researchers have focused on strategies to ensure long-term adherence to physical activity by the SCI population. Establishing goals (Bovend'Eerdts et al., 2009; Froehlich-Grobe et al., 2014; Wise et al., 2009), the theory of planned behaviour (Latimer & Martin Ginis, 2005), implementation intentions (Latimer et al., 2006a), action plans (Gainforth et al., 2014; Latimer-Cheung et al., 2013), and receiving group-mediated cognitive-behavioural training (GMBC) (Brawley et al., 2013) were successfully trialled by researchers. Additionally, social engagement may further increase physical activity participation (Gainforth et al., 2014).

The SMART goals method was developed to standardise specific, clear and personal objectives to guide rehabilitation and exercise programs (Bovend'Eerdts et al., 2009). It is a simple and efficient method that can be used in conjunction with the PSFS. Similar strategies were used by Wise et al. (2009) and Froehlich-Grobe et al. (2014), in which participants were encouraged to set specific goals and received phone calls from staff to re-evaluate aims over time. Participants improved physical outcomes and participation in follow-up assessments. The theory of planned behaviour supported that intentions were determinants of behaviour (Latimer & Martin Ginis, 2005) and a randomised controlled trial proved the efficacy of implementation intentions (Latimer et al., 2006a). In other words, participants responded well to establishing goals and determining when, where and how they were to be achieved.

Recent strategies have been tested by the same group of researchers, using motivational interviewing principles and group-mediated cognitive-behavioural training (Brawley et al., 2013; Latimer-Cheung et al., 2013). Motivational

interviewing is based on eliciting commitment to change by exploring values and motives for modifications (Latimer-Cheung et al., 2013). In individuals with SCI, this intervention resulted in significant ($P < .032$) medium to large-sized increases in goal-setting self-efficacy ($d = 0.72$), and intention strength ($d = 1.01$). A second study within the same publication analysed aspects of Bandura's Social Cognitive Theory (1997), in which sources of self-efficacy (i.e. mastery experience, vicarious experience, verbal persuasion, and psychological feedback) were stimulated by an exercise professional and a peer with paraplegia. Self-efficacy improvements were not significant ($P < .28$), unlike the improved number of strength training bouts ($d = 1.07$), duration ($d = 0.88$), and total minutes per week ($d = 0.96$) ($P < .024$).

Studies have demonstrated the importance of community participation in the adherence to physical activity. Brawley et al. (2013) obtained remarkable results by conducting group-mediated cognitive-behavioural training, using the group as an agent to facilitate and promote self-management and adherence. In this situation, participants virtually doubled the amount of total LTPA they performed per week (from 42.00 ± 69.57 min/week to 197.50 ± 270.86 min/week) after 9 weeks of intervention. Further details are displayed on **Table 2.3**. When stakeholders were integrated in society and directly involved with the implementation of physical activity action plans, adherence rates increased to a high 88% (Gainforth et al., 2014). In fact, another study stated that people with better community engagement had greater rehabilitation success, such as psychosocial adjustments and vocational practices (Krause et al., 2004). Therefore, community-based programs with direct involvement of the SCI population need to be promoted to increase adherence to physical activity.

Table 2.3. Self-regulatory interventions to increase physical activity participation among individuals with SCI.

Study subjects	Intervention	Outcome measures	Results
<p>Latimer and Martin Ginis (2005)</p> <p>Prospective correlational design</p> <p>N=104 adults with SCI 75 men and 29 women</p>	<p>Theory of planned behaviour for predicting leisure time physical activity (LTPA).</p>	<p>PARA-SCI; adjective pairs suggested by Ajzen to measure attitudes, subjective norms and intentions (2002); Armitage and Conner's (1999) seven-item measure of control-related constructs.</p>	<p>Attitudes ($\beta = .29$), subjective norms ($\beta = .29$), and perceived behavioural control ($\beta = .47$) each predicted LTPA intentions. LTPA intentions ($\beta = .45$) but not PBC ($\beta = .05$) predicted LTPA. Intentions mediated the attitudes–LTPA, subjective norms–LTPA, and PBC–LTPA relationships.</p>
<p>Latimer et al. (2006a)</p> <p>RCT</p> <p>N=54 adults with SCI 19 in implementation intention intervention group 18 in control group</p>	<p>Both groups received the physical activity tool kit and informed to participate in three 30-min bouts of moderate to heavy intensity physical activity per week over 4 weeks.</p> <p>The Intervention group also formulated implementation intention for promoting physical activity and received a physical activity logbook for self-monitoring.</p>	<p>PARA-SCI, Perceived Behavioural Control (PBC) questionnaire (likert-scales that measured three items assessed beliefs about the extent to which being physically active is personally controllable and three items assessed perceived ease or difficulty of engaging in physical activity).</p>	<p>At week 8, intervention reported more minutes of LTPA compared to control $F(1, 32)=4.76$, $P=.04$, $d=.52$. Treatment effects on intentions: $F(1, 33)=4.73$, $P=.04$, $d=.73$, and scheduling self-efficacy, $F(1, 34)=4.41$, $P=.04$, $d=.71$. Both intentions and scheduling self-efficacy were higher at follow-up in the intervention condition. No significant effects emerged for the PBC or barrier self-efficacy measures ($P < .05$).</p>
<p>Brawley et al. (2013)</p> <p>Pilot study of an intervention to increase self-managed physical activity</p> <p>13 adults with SCI from LTPA program.</p>	<p>9-week Group-mediated cognitive-behavioural training (GMBC) intervention designed to promote self-regulatory skills and increase the amount of time spent in LTPA outside the supervised program.</p>	<p>Leisure Time Physical Activity Questionnaire for People with SCI (LTPAQ-SCI); Likert-scales for self-efficacy for scheduling and planning, physically meaningful outcomes, understanding of intervention content, learning outcomes, satisfaction, and perceptions of the group environment.</p>	<p>LTPA increased from 42 ± 69.57 min/week to 197.5 ± 270.86 min/week; $P < .05$; self-regulatory skills, self-regulatory efficacy were sustained and action planning increased from 4.63 ± 3.25 to 6.83 ± 2.40; $P=.06$.</p>
<p>Latimer-Cheung et al. (2013)</p> <p>Two pilot studies on motivational counselling and peer-mediated interventions</p> <p>11 men and women with paraplegia</p>	<p>Study 1: single telephone call counselling session on self-regulatory efficacy, intentions, and action plans for LTPA</p> <p>Study 2: home-based strength-training session, delivered by a peer and a fitness trainer, on strength-training task self-efficacy, intentions, action plans, and behaviour.</p>	<p>LTPAQ-SCI, six-item health care climate questionnaire, yes/no answers whether participants found the session helpful (yes/no), and open-ended questions regarding specific intervention components.</p>	<p>Counselling session (Study 1): significant ($P < .032$) medium- to large-sized increases in participants' confidence to set LTPA goals ($d=0.72$) and intentions to be active ($d=1.01$).</p> <p>Home visit (Study 2): not significant. Self-efficacy improvements ($P < .28$), however significant number of bouts of strength training ($d=1.07$), duration ($d=0.88$), and total minutes per week ($d=0.96$) ($P < .024$).</p>

Regardless of the overwhelming evidence of the benefits of physical activity and existence of successful adherence strategies, daily levels of physical activity recorded by people with SCI are usually not sufficient for conditioning purposes (Martin Ginis et al., 2010e). An alarming 50% of this population does not practice any type of physical activity. Numerous barriers are responsible for these low rates such as physical impairment, psychosocial problems, environmental obstacles, and lack of financial support (Kehn & Kroll, 2009; Vissers et al., 2008). One of the key messages in the 2013 World Health Organisation report, *International Perspectives in Spinal Cord Injury* (Australian Human Rights Commission) was everyone's social responsibility in removing barriers and providing adequate support for people with SCI to minimise poverty and social exclusion associated with this condition. Understanding these barriers is the first step to assisting people with disabilities.

2.7 BARRIERS AND FACILITATORS FOR PHYSICAL ACTIVITY

As stated previously, the *Convention on the Rights of Persons with Disabilities* (2006) reassures the rights of people with disabilities to dignity, autonomy, community inclusion, equal opportunities, and accessibility to all environments. In practice, these rights are often not respected and individuals with SCI are generally excluded from society (World Health Organization, 2013). In addition to difficulties imposed by physical impairments, SCI populations face environmental and architectural barriers, discrimination in the work setting, attitudinal affronts, psychological problems, and limited opportunities for social and physical activity engagement after rehabilitation (Charlifue & Gerhart, 2004; Scelza et al., 2007). Reduced employment opportunities and greater expenses with medical support led to financial constraints and eventual decline in health status (Cao et al., 2011).

Physical activity is an effective option for addressing many problems mentioned above, enabling social inclusion, health, and life satisfaction (Martin Ginis, Jörgensen, & Stapleton, 2012g). In order to encourage increased uptake of such practices, factors that inhibit and facilitate physical activity participation in SCI cohorts need to be well understood. Several researchers from North America (Kehn & Kroll, 2009; Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004; Scelza, Kalpakjian, Zemper, & Tate, 2005), Europe (Vissers et al., 2008), and Australia (Kirkby, Cull, & Foreman, 1996; Robertson, Bucks, Skinner, Allison, & Dunlop, 2011) conducted interviews and surveys to identify the sources of obstacles. Two

systematic reviews gathered forty-seven different studies involving SCI populations to analyse factors that impact fitness training and sports participation (Fekete & Rauch, 2012; Jaarsma, Dijkstra, Geertzen, & Dekker, 2014). The majority of studies applied cross-sectional designs involving qualitative and quantitative approaches, with the exception of five randomized controlled trials (Arbour-Nicitopoulos et al., 2009; Bassett & Martin Ginis, 2011; Froehlich-Grobe et al., 2014; Latimer et al., 2006a; Wise et al., 2009). Findings on barriers and facilitators to physical activity are discussed below.

2.7.1 Barriers for physical activity

Low physical activity participation rates among the SCI population have been attributed to multiple issues related to personal and environmental barriers (Fekete & Rauch, 2012; Kehn & Kroll, 2009; Rimmer et al., 2004; Scelza et al., 2005). Difficulties were reported early on during the rehabilitation period, where services focused on the recovery of functional activities and failed to emphasise full reintegration of patients in their communities (Levins et al., 2004; Scelza et al., 2007; Vissers et al., 2008). The majority of patients with SCI were not adequately informed by their primary health care provider on options and benefits of physical activity participation (Kehn & Kroll, 2009; Rimmer, 2000; Scelza et al., 2005). Once discharged from rehabilitation services, perceptions of barriers change overtime and may be influenced by a diverse range of factors (Vissers et al., 2008). Features such as the individual's age, race, socioeconomic status, severity of SCI, time since injury, personality, and how well they adapt to the situation need to be considered to comprehend the impact of barriers (Martin Ginis et al., 2010e).

Extensive review studies on barriers and facilitators to physical activity concluded that most articles presented low levels of evidence, though participation was clearly associated to intrinsic and external factors (Fekete & Rauch, 2012; Jaarsma et al., 2014). Difficulties with wheelchair accessibility and lack of options of adapted sports, proper assistance, appropriate equipment, and transportation services were cited across studies (Jaarsma et al., 2014; Kehn & Kroll, 2009; Levins et al., 2004). Socio-demographic features associated to low rates of physical activity included advanced age, unemployment, low socioeconomic status, being single and/or of female gender (Fekete & Rauch, 2012; Rauch, Fekete, Cieza, Geyh, & Meyer, 2013). Reduced levels of motivation, lack of energy, fatigue, secondary

health complications and the disability itself were additional sources of inactivity (Jaarsma et al., 2014; Kehn & Kroll, 2009).

The main questionnaire utilised in literature to study physical activity barriers among individuals with SCI has been the *Barriers to Physical Activity and Disability Survey* (B-PADS) (Rimmer, 2000; Rimmer, Riley, & Rubin, 2001; Robertson et al., 2011; Scelza et al., 2005). B-PADS is a valid and reliable measure of factors that impact physical activity participation (Rimmer et al., 2001). It was significantly correlated to absolute peak VO_2 , absolute peak VO_2 , maximum workload, and time to exhaustion ($P < .05$); and Cronbach α coefficients ranged from .78 to .95 for test-retest and .92 to .99 for inter-rater reliability testing. A couple of studies utilised the *Physical Activity Scale for Individuals with Physical Disabilities* (PASIPD) (Gutierrez, Thompson, Kemp, & Mulroy, 2007; Liang et al., 2008). PASIPD was also validated (Washburn, Zhu, McAuley, Frogley, & Figoni, 2002) and focuses on participation, but does not directly assess barriers for training. The *Disability Sport Participation Questionnaire* (DSPQ) developed by Wu and Williams (2001) evaluates factors influencing sports participation. Though it captured barriers relevant to sports participation and presented strong test-retest reliability ($r = 0.86$), the DSPQ may not be suitable for general fitness training and validity studies are further warranted. Given the construct validity and inter-rater reliability, B-PADS is an adequate objective measure of barriers to physical activity for people with SCI living in the community.

Using a preliminary version of B-PADS, Rimmer (2000) assessed African American women with severe disabilities. The main barriers to physical activity detected were costs (84.2%), lack of energy (65.8%), transportation (60.5%), and not knowing where to exercise (57.9%). Scelza et al. (2005) later applied the survey specifically in a SCI cohort of North America. In this case, personal concerns affected physical activity participation the most regarding motivation (54.2%), energy (41.7%), and interest (33.3%). Among the environmental impediments, once again costs (40.4%) were frequently cited, followed by information (36.1%), and time constraints (31.9%). Other barriers commonly reported were facility access and lack of experience among exercise professionals in working with people with disabilities (Kehn & Kroll, 2009; Scelza et al., 2005). They also detected that tetraplegia and high stress levels presented negative associations to physical activity engagement. Similarly, a study conducted in Western Australia analysed perceptions towards barriers according to the individual's physical limitation in the local SCI community (Robertson et al., 2011). Wheelchair users frequently reported lack of a personal care

attendant (50%), concerns about incontinence (49%), lack of access to an appropriate facility (47%), costs (44%) and feeling uncomfortable in a fitness centre (41%); whereas people with independent gait were more concerned with lack of energy (42%), pain (40%) and cost associated to training (32%). Similar to other studies of this nature (Kehn & Kroll, 2009; Scelza et al., 2005), low response rates were obtained (21.7% out of 336 people) and no research to date has analysed perceptions towards barriers and facilitators in the community and fitness centres, suitable locations for public health initiatives targeting people with disabilities.

Results from the aforementioned studies reveal the necessity of community-based physical activity programs, addressing barriers and promoting health among individuals with SCI (Rimmer & Henley, 2013). The use of community-based facilities needs to consider cost reduction, proximity to fitness centres, and proper assistance for exercising. Strategies that improve motivation and adherence to training programs are also essential to guarantee the success of public health initiatives (Latimer & Martin Ginis, 2005; Martin Ginis & Bray, 2010). The following section further explores factors that facilitate increased physical activity levels and community participation post-SCI.

2.7.2 Facilitators for physical activity

Less attention has been directed to the research of drivers for physical activity engagement compared to barriers research in SCI. For the study of facilitators, no validated instrument was identified and most studies on the topic conducted qualitative thematic analysis (Kehn & Kroll, 2009; Levins et al., 2004; Vissers et al., 2008). Kehn and Kroll (2009) and Levins et al. (2004) developed similar interview guidelines to obtain information on perceived barriers and facilitators for training. Questions on characteristics of the SCI, rehabilitation experience, information on physical activity regimes, and future plans formed the basis of discussions. Their semi-structured interview guides were the most adequate and comprehensive set of open-ended questions available at the time of this study targeting SCI populations. The aforementioned literature suggests that such qualitative method is able to provide in-depth information on barriers and facilitators for the execution of structured physical activity programs in community fitness centres. Therefore, one-on-one interviews and subsequent thematic analysis needed to be conducted among individuals with SCI to understand their main concerns regarding physical activity training.

In previous studies, facilitators were usually classified under intrinsic (e.g. motivation, self-efficacy, and socio-demographic features) and external factors (social involvement, accessibility, goal setting, and physical activity opportunities) (Jaarsma et al., 2014; Levins et al., 2004). Most studies infer the facilitation process through the elimination or reduction of identified obstacles. However, many problems identified were linked to lifestyle choices. Behavioural changes have shown to be far more complex to instate, requiring additional efforts from health professionals and society to promote motivation and inclusive environments (Brawley et al., 2013; Latimer-Cheung et al., 2013; Latimer et al., 2006a; Ryan, Patrick, Deci, & Williams, 2008).

Researchers found people with SCI more likely to participate in community and physical activity if presenting the following demographic characteristics: less extensive neurological injury, longer duration of SCI, younger age, and being of male gender (Rauch et al., 2013; Schopp et al., 2007), though not exclusively. In fact, other researchers did not correlate activity participation to the neurological level of injury or duration of the SCI (Bauman et al., 2012; Kehn & Kroll, 2009). Higher income and education were more substantial environmental factors known to increase involvement (Jaarsma et al., 2014; Kehn & Kroll, 2009). Among the personal motivators were enjoyment, interest in sports and physical activity, as well as greater levels of self-efficacy (Jaarsma et al., 2014). Having a physically active life-style pre-injury was another indicator of inherent interest and knowledge on benefits of physical activity (e.g. maintaining optimal health and preventing secondary problems) (Kehn & Kroll, 2009). Better adjustment to the SCI and the desire to achieve high levels of independence were further featured as facilitators in qualitative studies (Kehn & Kroll, 2009).

In many cases, adaptation was closely linked to the quality of rehabilitation received shortly after the injury and social support received from family and friends (Kehn & Kroll, 2009; Vissers et al., 2008). Professional guidance during rehabilitation included re-orientation of expectations, alternative forms of activities, and stimulation to maintain physically active lifestyles (Kehn & Kroll, 2009; Vissers et al., 2008). Following discharge, community involvement and team sports were found to be motivating due to their social aspect (Levins et al., 2004). Tailored-made recommendations were another aspect valued by individuals with SCI (Elley, Dean, & Kerse, 2007; Jaarsma et al., 2014; Latimer, Brawley, & Bassett, 2010; Rhodes, Courneya, & Jones, 2004). Along with professional orientation, peer-mentoring was suggested by many authors as another powerful source of information (Levins et al.,

2004). Access to knowledge on their condition and supply of resources were found to empower individuals with SCI, which resulted in profound involvement of stakeholders with community programs (Raeburn, Akerman, Chuengsatiansup, Mejia, & Oladepo, 2006).

Community-based physical activity programs

As observed in **Section 2.7.1. Barriers to physical activity**, the transitional phase between discharge from hospital-based services and the continuity of health maintenance presents gaps and patients are often left without guidance. Interventional studies have attempted to address these issues by trialling the effectiveness of community-based physical activity programs for SCI populations (Froehlich-Grobe et al., 2014; Gainforth et al., 2014; Pelletier, 2014; Wise et al., 2009). Strategies that optimised physical and psychosocial outcomes included structured physical activity programs during the rehabilitation period (Pelletier, 2014) and direct referral systems from health-care providers to physical activity programs in the community (Pelletier, Latimer-Cheung, Warburton, & Hicks, 2014; Rimmer & Marques, 2012); written and audiovisual guidance (Wise et al., 2009); supply of small exercise equipment suitable for homes (e.g. resistance tubes and bands, free weights, body blades, etc.); support from health professionals (Froehlich-Grobe et al., 2014; Pelletier, 2014); goal setting; and regular re-assessment of aims (Froehlich-Grobe et al., 2014; Pelletier, 2014; Wise et al., 2009). Only Wise et al. (2009) did not encounter significant differences between supervised and unsupervised groups, suggesting that exercise professionals need to consult their clients and prescribe activities according to their needs.

A meta-analysis conducted in 2007 noticeably favoured exercise referral schemes to supervised physical activity programs in public leisure facilities for the uptake of moderate exercise routines (Williams, Hendry, France, Lewis, & Wilkinson, 2007). A transitional *therapist-to-trainer* model was recently proposed to expedite the reintegration of individuals with SCI in community-based fitness facilities (Rimmer & Henley, 2013). It is based on inter-professional collaboration between rehabilitation and certified exercise professionals on the development of adequate exercise plans for neurological patients at home or fitness centres. Rimmer and Henley (2013) cite the example set by the Lakeshore Foundation in Birmingham (Alabama), a fully accessible and affordable fitness facility nearby public transportation; equipped with endurance and weight training machines adequate for universal use; offering a diverse range of classes; and staffed with

exercise physiologists, adapted physical activity trainers, and certified exercise professionals. This is an ideal setting for the promotion of physical activity among people with disabilities. However, there is a scarce availability of such facilities. It may be hypothesised that utilising the infrastructure of community fitness centres and providing certified training for exercise professionals would help abate obstacles that currently deny motivated individuals with SCI participation in healthy living activities.

Exercise professionals

An exercise professional is defined as a certified trainer who uses an individualised approach to assess, motivate, educate, and instruct clients regarding their health and fitness needs (Malek, Nalbone, Berger, & Coburn, 2002; National Strength and Conditioning Association, 2011). A solid understanding of physical activity prescription and knowledge in special populations was considered of critical importance to guarantee safety and efficiency in the work environment (Hootman, 2009; Kehn & Kroll, 2009; Malek et al., 2002; Martin Ginis et al., 2010a). Exercise professionals have played a fundamental role in health promotion by reverting poor patient adherence rates in exercise referral schemes (Moore, Moore, & Murphy, 2011; Williams et al., 2007). They helped provide support and guidance on the development of autonomy, competency, and ultimately behavioural changes among patients (Rimmer & Henley, 2013; Rimmer & Marques, 2012). This argument was supported by the self-determination model, in which external regulation delivered by health professionals was believed to influence the internal regulation of patient behaviour overtime (Ryan et al., 2008). Extrinsic motivation strategies have shown effective preliminary results (Latimer-Cheung et al., 2013) and deserve additional investigation.

As stated previously, efficient sessions need to consider physical and psychological adjustments that effect on LTPA engagement following SCI. Along with health promoting physical activity targets (described in section 2.5.3. *Physical Activity Guidelines for Individuals with SCI*), exercise professionals are recommended to include interventions that foster intrinsic motivation, such as self-esteem and self-efficacy, or integrated extrinsic motivation, namely self-determination among individuals with SCI (Peter, Muller, Cieza, & Geyh, 2012; Ryan et al., 2008). These positive psychological constructs have been endorsed by several researchers and resulted in encouraging outcomes (Brawley et al., 2013; Latimer-Cheung et al., 2013; Siegel, 2009); nevertheless, self-esteem, self-efficacy,

and self-determination are only a few concepts within a wide range of psychological resources that can potentially help clients with SCI.

Lack of information regarding positive personality attributes currently inhibit health professionals from exploring and strengthening individual's personality attribute and good habits among the SCI population. The identification of relevant personal attributes may be highly advantageous on the prediction of physical activity behaviour, development of tailored interventions, and enhancing inner strengths of individuals with SCI. Therefore, the subsequent section reports on literature associated to positive personality attributes and models that formed the basis for the third study (**Chapter 5. Study 3. Analysis of Personality Attributes in Clients as Predictors of LTPA**).

2.8 POSITIVE PSYCHOLOGY AND PERSONALITY ATTRIBUTES

The conceptualisation of disability has undergone significant changes in the past century. The focus has been gradually moving away from the medical model, in which disabilities need to be aided, onto a social-ecological model of human functioning (Shogren, 2013). The principals of Positive Psychology have been acknowledged for several decades; nevertheless researchers attributed more authenticity and importance to the negatives of pathologies and remedial treatments. This reflects a natural tendency given that negative experiences provide a sense of urgency and danger, overriding positive ones. The Positive Psychology movement believed the cure of ailments often did not address fundamental issues of existence and patients found themselves detached from positive emotions. Seligman and Csikszentmihalyi (2000) were the first to accumulate a body of empirical evidence on the subject and offer an alternative and more holistic paradigm. Instead of focusing on the negatives, Positive Psychology shifted the attention to constructive features that increase a person's purpose in life.

Positive Psychology studies of the past two decades have largely attributed quality of life to "positive subjective experiences, positive individual traits, and positive institutions" (Seligman & Csikszentmihalyi, 2000). Seligman and Csikszentmihalyi (2000) aimed at recovering the importance of hope, wisdom, creativity, future mindedness, courage, spirituality, responsibility, and perseverance on the promotion of general well-being and prevention. In fact, principals of Positive

Psychology and Rehabilitation Psychology align on many terms to promote health and independence (Dunn, Uswatte, Elliott, Lastres, & Beard, 2013). These models do not attempt to undermine the pathology and barriers, but rather endorse client-centred approaches to determine intervention strategies according to their personality and functional strengths (Claes, Van Hove, Vandeveld, van Loon, & Schalock, 2010).

Researchers, health professionals and policy makers have highlighted the importance of discovering psychosocial factors to clinical states through Positive Psychology (Dunn et al., 2013). These psychosocial health correlates and determinates can be fostered and used against the main risk factors to health in modern society: inactivity, high blood pressure, tobacco use, high blood glucose, and overweight and obesity (World Health Organization, 2009). Evidence from extensive systematic reviews supports increased physical activity behaviour as an effective low-cost preventive and treatment measure via improved fitness and strength (Devillard, Rimaud, Roche, & Calmels, 2007; Hicks et al., 2011; Martin Ginis et al., 2011a; Valent et al., 2007). However, the percentage of inactive people with SCI is generally higher compared to the general population. Fifty percent of the SCI population is inactive (Martin Ginis et al., 2010e), compared to 31.1% among able-bodied adults world-wide (Hallal et al., 2012). The SCI population is at heightened threat by most risk factors due to secondary physiological dysfunction, socio-environmental barriers, and lack of motivation (Kehn & Kroll, 2009; Kroll, Neri, & Ho, 2007g; Martin Ginis et al., 2010e).

Regarding physical activity participation, researchers have focused on the association between constructive personality *traits* (i.e. higher extraversion, higher conscientiousness, and lower neuroticism) with improved health related behaviours (Ingledew, Markland, & Sheppard, 2004). Preliminary evidence in athletes with SCI encouraged sports participation for increased levels of extraversion and reduced anxiety/depression (Gioia et al., 2006). Personality traits are generally ingrained features and less malleable towards extrinsic input (Park & Peterson, 2009). In contrast, positive personality *attributes* such as motivation, self-efficacy, self-determination, and perseverance are more responsive to physical activity and fundamental for the success of interventions in people with SCI (Brawley et al., 2013; Latimer-Cheung et al., 2013; Park & Peterson, 2009; Ryan et al., 2008).

Positive psychology has been applied on abled-bodied counter-parts detecting different personality strengths that predicted different outcomes (Park & Peterson, 2009; Seligman & Csikszentmihalyi, 2000). Park and Peterson (2009) developed the

Values in Action (VIA) Project to describe personal assets and those of others that cultivate character according to an individual's strength profile. They determined that the encouragement of character strengths such as perseverance, love, gratitude, hope, intelligence, and humour can lead to improved knowledge, health, and social relationships. Such personality strengths, if properly identified and stimulated, exert positive effects in the academic, health and political environments (Park, 2004; Park, Peterson, & Seligman, 2004; Park & Peterson, 2009).

Strong personality attributes are part of psychological resources, a valuable set of abilities, knowledge, and behavioural patterns that can be fostered to achieve effective health outcomes (Peter et al., 2012). Information on their influence upon physical activity patterns can help health professionals predict rehabilitation progress and direct focus on motivating certain modifiable attributes. As mentioned previously, the understanding and promotion of positive personality attributes in people with disabilities is closely linked to rehabilitation psychology (Chou, Lee, Catalano, Ditchman, & Wilson, 2009). According to this line of theory, positive perspectives could be the precursors of health, social integration, autonomy and well-being. Thereby, interventions based on Positive Psychology principals would emphasise healthy behaviours and enable the prevention of pathologies (Dunn et al., 2013).

Personality-wise, people with SCI tend to be described as risk takers, action driven, extraverted, impulsive, and excitement seekers (Rohe & Krause, 1999). These characteristics increased the risk of SCI, though personal traits hardly change post-injury (Griffiths, Clinpsy, & Kennedy, 2012); that is, determination and drive are likely to be retained or even enhanced following SCI. These attributes can be channelled into physical activity uptake and help shape their lives and purposes following a life changing injury. Positive Psychology endorses the identification of constructive features and their daily practice for character development and improved mental well-being (Park & Peterson, 2009). Insight into other personality attributes through Positive Psychology and their promotion can be useful to strengthen signature qualities and reverse unhealthy behaviours among the SCI cohort (Park & Peterson, 2009; Rohe & Krause, 1999). Unfortunately, very little information is available regarding the impact of personality attributes on physical activity behaviour (Peter et al., 2012) and the personality assessments available are not specific to the SCI population.

To the date, no assessment models have been developed for the evaluation of personality attributes in exercise professionals and clients with SCI. The closest

instrument to subject would be the *VIA Inventory of Strengths* (VIA-IS), widely used measurement for personality studies (Park & Peterson, 2009). VIA-IS is a lengthy assessment (evaluates 24 character strengths in 45 minutes on average) and involves contexts irrelevant to the physical activity realm. Similarly, the conceptual framework of human functioning adopted by the American Association on Intellectual and Developmental Disabilities' (American Association on Intellectual and Developmental Disabilities & Schalock) enhances each individual's ability, though it is also very broad and better applied to individuals with intellectual and developmental disabilities (American Association on Intellectual and Developmental Disabilities & Schalock, 2012). The only instrument specific to people with SCI found in the exercise setting (i.e. *SCI Exercise Self-Efficacy Scale*) presented high reliability (Cronbach's alpha = .9269) but poor to moderate construct validity (Spearman RHO = .316) compared to the *Generalised Self-Efficacy Scale*, and focused only one construct: self-efficacy (Kroll, Kehn, Ho, & Groah, 2007a). Other tools presented additional flaws regarding specificity and uncertain psychometric properties (Kroll et al., 2007a).

In order to address the assessment issues mentioned above, steps need to be taken towards the investigations of personality attributes of exercise professionals and clients with SCI that may influence physical activity behaviour. First, intra-personal and interpersonal attributes between the two cohorts should be identified. Second, their surroundings and interpersonal relationships require improved understanding and definition as they influence a great deal on one's behaviour (Dunn et al., 2013). Third, an assessment instrument needs to be developed according to the information obtained by individuals with SCI and exercise professionals to test and document findings (Buntinx, 2013). These tools could reveal personality attributes that require nurturing and development, and help the prediction of physical activity behaviour among individuals with SCI.

2.9 SUMMARY AND IMPLICATIONS

SCI is a life changing experience with extensive physical, physiological, and psychosocial repercussions. The *Convention on Human Right for People with Disabilities* guarantees these individuals access to rehabilitation and equitable opportunities. However, people with SCI are faced with several issues regarding sensory-motor impairments, social injustice, environmental and architectural obstacles. These difficulties preclude optimal health maintenance especially post-discharge from rehabilitation services. Barriers in the community need to be identified, removed or adapted, and coupled with facilitators for physical activity participation and health promotion. Once barriers and facilitators investigations are completed, this information can be used to develop safe and structured physical activity programs in community fitness centres across various locations.

Translational research in community adapted training is still in its infancy and such public health promotion strategies need to be developed, executed and evaluated (Block et al., 2010; Froehlich-Grobe et al., 2014; Rimmer & Henley, 2013; Wise et al., 2009). Literature suggests that the elimination of significant barriers (e.g. costs, transportation, and lack of assistance) and the implementation of motivational prompts (e.g. goal setting and scheduled sessions with exercise professional supervision) may lead to higher levels of physical activity engagement among the SCI community, as well as improved psychosocial well-being. (Bauman et al., 2012; Kehn & Kroll, 2009; Kohl et al., 2012; Latimer et al., 2006a; Rimmer & Marques, 2012; Rimmer et al., 2004). The identification of positive personality attributes between clients with SCI and their respective exercise professionals could reveal important personality attributes for the prediction and encouragement of physical activity behaviour.

2.10 OBJECTIVES

In order to address the issues observed in literature, the specific objectives of this thesis were to:

Study 1 (Chapter 3)

- Identify the barriers and facilitators to physical activity among community dwelling individuals with SCI through semi-structured interviews;
- Understand differences between the barriers and facilitators perceived by individuals with SCI that participate in high or low levels of physical activity;
- Observe perception changes after a structured physical activity program.

Study 2 (Chapter 4)

- Promote re-integration of inactive people with SCI into physically active life styles post-discharge from rehabilitation services through an eight-to-twelve week customised physical activity program (i.e. SCIPA Com);
- Evaluate whether access to qualified exercise professionals and accessible fitness centres at a low cost improves physical activity levels performed by people with SCI across different periods (baseline, immediately after SCIPA Com, three and six months after SCIPA Com);
- Document the association between physical activity levels and functional goal achievement, self-esteem, and quality of life among individuals with SCI.

Study 3 (Chapter 5)

- Identify positive personality attributes deemed relevant to clients with SCI and exercise professionals in order to enhance LTPA levels among individuals with SCI;
- Develop two positive personality attributes assessment instruments, one for clients with SCI and another for exercise professionals, to test their prediction capacity regarding LTPA levels after a physical activity intervention program based on their goals, personality and physical strengths and overtime.

2.11 HYPOTHESES

From the review of the related literature the following hypothesis have been generated:

Study 2 (Chapter 4)

- That a model of health promotion for active and inactive individuals with SCI in community fitness centres can lead to increased levels of physical activity, function, quality of life, self-esteem, and community integration among this cohort.
- That functional goal achievement, self-esteem, and quality of life are directly associated to physical activity levels.
- That increases in levels of physical activity, function, quality of life and self-esteem will be higher in the previously inactive SCI population.
- That changes to baseline physical activity levels will be significant after experiencing a supervised eight-to-twelve week physical activity program and maintained in the follow-up assessment periods.

Study 3 (Chapter 5)

- That positive personality attributes assist the prediction of LTPA levels after a physical activity program based on their goals, personality and physical strengths;
- That high-levels of positive personality attributes results between clients' and exercise professionals perspectives will display better LTPA outcomes than those with discordant assessments.

Chapter 3: Barriers and Facilitators for Physical Activity among Individuals with SCI

STUDY 1

This chapter outlines *Study 1*, the study of barriers and facilitators to physical activity among community dwelling individuals with SCI. The following sections describe this first study conducted within the *Spinal Cord Injury and Physical Activity in the Community* (SCIPA Com) program:

Section 3.1 Introduction to problems regarding barriers to physical activity among individuals with SCI.

Section 3.2 Methodology used to collect quantitative data on barriers for physical activity and qualitative information on history and perspective towards benefits, barriers and facilitators for physical activity.

Section 3.3 Information on participants with SCI, belonging to either the physically active or inactive groups.

Section 3.4 Procedures used to assess participants before and after their participation in a structured physical activity program.

Section 3.5 Measures and instruments adopted for this study (the Barriers to Physical Activity and Disability Survey and the semi-structured interview guide).

Section 3.6 Quantitative and qualitative approaches used to analyse data.

Section 3.7 Results obtained via questionnaire and interviews.

Section 3.8 Discussion of the findings on barriers and facilitators to physical activity for the SCI population, as well as associated literature.

Section 3.9 Conclusions extracted from *Study 1*. And finally

Section 3.10 Limitations of the research.

3.1 INTRODUCTION

Studies world-wide have accumulated irrefutable evidence on the benefits of physical activity in improving fitness and social integration among communities (Deuster & Silverman, 2013; Mendes, Sousa, & Barata, 2011; Vuori, Lavie, & Blair, 2013). This is especially true for people with spinal cord injury (SCI), who are at a higher risk of developing cardiovascular, respiratory, and metabolic complications (Galea, 2012; Gater, 2009; Martin Ginis et al., 2012g; Rauch et al., 2013). Physical activity is associated with the prevention of secondary health problems, enhanced functional abilities, and improved self-confidence, ultimately increasing the possibilities of individuals with SCI leading independent lives (Fullerton et al., 2003; Jacobs & Nash, 2004; Kerstin, Gabriele, & Richard, 2006; Myslinski, 2005; Nash, 2005). Those considered active also experienced reduced pain, anxiety, depression, mortality rates (Hicks et al., 2003; Krause et al., 2004) and advantages such as increased energy and quality of life (Anneken et al., 2010; Gioia et al., 2006; Tawashy et al., 2009). Early prevention can also lead to potential cost savings with less need for hospitalization, powered mobility aids, and additional personal care (Ackery et al., 2004).

Daily levels of physical activity of people with SCI are usually not sufficient for conditioning purposes and approximately half of this population is sedentary (Martin Ginis et al., 2010e). The consequences of inactivity include increased risk of chronic diseases and physical capacity decline. This deterioration is evident when individuals with SCI present muscle weakness, reduced bone mineral density, pain, fatigue and predominantly cardiorespiratory and/or psychosocial complications (Devillard et al., 2007; Martin Ginis et al., 2010d; Martin Ginis et al., 2010e; Martin Ginis et al., 2003; Tawashy et al., 2009). A review of published literature has shown that life satisfaction among individuals with SCI is reduced compared to able-bodied counterparts, in addition to being at a higher risk of developing depression, anxiety, and posttraumatic stress disorder (Post & van Leeuwen, 2012). As mentioned previously, these complications can be improved or prevented through healthy lifestyles. Therefore, in order to encourage physical activity uptake among individuals with SCI, it is first necessary to understand the barriers and facilitators towards it. Secondly, action plans such as structured training programs need to be developed, implemented and evaluated (Gainforth et al., 2014; Latimer-Cheung et al., 2013).

Previous studies have attributed low participation rates mainly to: negative experiences throughout rehabilitation; personal issues and environmental barriers; all regularly faced by people with SCI (Fekete & Rauch, 2012; Jaarsma et al., 2014; Kehn & Kroll, 2009; Rimmer et al., 2004; Scelza et al., 2005). Following a SCI, several researchers have reported a lack of appropriate assistance and guidance regarding physical activity practices during treatment and post hospital discharge (Kehn & Kroll, 2009; Rimmer & Henley, 2013; Rimmer et al., 2004; Vissers et al., 2008). In the community, common accessibility barriers to physical activity include facilities unsuitable for wheelchair manoeuvrability, lack of transportation, inadequate equipment, costs associated with an exercise program, and absence of suitable assistance (Cowan, Nash, & Anderson, 2013; Kehn & Kroll, 2009; Levins et al., 2004; Scelza et al., 2005; Vissers et al., 2008). Involvement in organised sports is limited due to minimal options and lack of information (Jaarsma et al., 2014). Additionally, personal barriers include lack of motivation, severity of the SCI, advanced age, health issues, fatigue and financial difficulties (Fekete & Rauch, 2012; Jaarsma et al., 2014; Kehn & Kroll, 2009).

Fortunately, a number of facilitators to physical activity and sport have been identified. Jaarsma et al. (2014) analysed 52 studies on barriers and facilitators to sports participation. They concluded that fun, health, and fitness were personal facilitators for people with disabilities. Increased motivation, self-efficacy, and goal setting led to further engagement in sport. Previous positive experience with physical activity predicted greater participation, as did support from family, friends, and society in general (Kehn & Kroll, 2009; Vissers et al., 2008). Having a good understanding of their condition and awareness of options in the community stimulated greater social involvement and empowered individuals to seek more physical activity opportunities (Raeburn et al., 2006).

Community-based physical activity interventions have been trialled in the SCI population to reduce inactivity (Block et al., 2010; Froehlich-Grobe et al., 2014; Gainforth et al., 2014; Pelletier, 2014; Wise et al., 2009). These studies adopted several measures that aimed to increase physical activity in the SCI population by a) promoting community development initiatives to prepare service providers to assist people with SCI (Gainforth et al., 2014); b) adopting a referral system between rehabilitation services to health and fitness facilities (Pelletier et al., 2014; Rimmer & Henley, 2013); c) supplying people with SCI equipment and guidance on effective forms of exercise (Froehlich-Grobe et al., 2014; Latimer-Cheung et al., 2013; Wise et al., 2009); and d) counselling and cognitive-behavioural interventions to improve

one's motivation, exercise self-efficacy, and self-regulation (Brawley et al., 2013; Latimer-Cheung et al., 2013; Latimer et al., 2006a). Such interventions have led to significant physical and psychosocial improvements among the SCI population.

Within the community, health and fitness centres are suitable locations for the promotion of public health initiatives that adopt inclusive approaches. They are usually in proximity to the homes of people with SCI, as opposed to institutionalised facilities (i.e. hospitals and specialised rehabilitation centres) and may offer a cost-efficient option for physical activity engagement. Improved understanding of the elements that contribute to high or low physical activity levels in the community and gyms could support effective evidence-based health promotion strategies for the SCI population throughout society (Bauman et al., 2012; Kehn & Kroll, 2009; Kohl et al., 2012; Rimmer & Marques, 2012; Rimmer et al., 2004).

No research to date has analysed if a structured physical activity program conducted in community fitness centres could influence perceptions about barriers and facilitators among adults with SCI. Translational research in community settings using adapted training is still in its infancy and health promotion strategies need to be developed, implemented and evaluated (Bauman et al., 2012; Kehn & Kroll, 2009; Rimmer & Marques, 2012). Therefore, the SCIPA Com program was developed to address issues and promote community-based physical activity participation among individuals with SCI.

3.1.1 Background

The *Spinal Cord Injury and Physical Activity* (SCIPA) project is a multi-centre research organisation across Australia and New Zealand lead by spinal units and universities from the aforementioned countries. The overall objective of SCIPA is to understand the effects of physical activity and exercise in recovery, health and wellbeing after SCI and increase physical activity levels.

There are four main projects that comprise SCIPA: Hands-On, Full-On, Switch-On, and the present study, SCIPA Com. The first three are multi-centre randomised control trials executed in rehabilitation institutions. Switch-On encompasses early intervention after SCI using functional electrical stimulation (FES)-cycling and passive cycling to prevent musculoskeletal depletion; Hands-On focuses on upper-limb rehabilitation for patients with tetraplegia utilising FES-assisted exercises (Harvey, Dunlop, Churilov, Hsueh, & Galea, 2011); and Full-On compares the effect of an intensive whole-body workout with traditional upper body

strengthening and endurance training (Galea et al., 2013). SCIPA Com is the only community-based study under the SCIPA program, and involves the safe return of individuals with SCI into physically active life-styles post-discharge from rehabilitation services. This thesis only reports work from SCIPA Com.

This chapter focuses on the first (*Study 1*) of the three studies conducted within SCIPA Com. *Study 1* was conducted in two phases: before and after SCIPA Com. Phase One aimed at identifying barriers and facilitators towards physical activity among community dwelling individuals with SCI to inform the development of individualised physical activity programs. This information provided the basis of the SCIPA Com intervention program. In Phase Two, the main objective was to analyse perceptions towards physical activity subsequent to an eight-to-twelve week customised physical activity program provided in this study. Further details on SCIPA Com and associated physical and psychological outcomes are covered in *Studies 2* and *3* (in **Chapters 4** and **5**, respectively).

3.1.2 Research questions

The research questions that guided *Study 1* were:

- What are the barriers that limit individuals with SCI from performing physical activity?
- What facilitates the participation of people with SCI in physical activity?
- Are there any differences between the barriers and facilitators perceived by highly active individuals with SCI compared to inactive individuals with SCI?
- Do perceptions on barriers and facilitators to physical activity change after being exposed to a structured physical activity program?

3.1.3 Objectives

The main objectives of *Study 1* were to:

- Identify the barriers and facilitators to physical activity among community dwelling individuals with SCI through semi-structured interviews;
- Understand differences between the barriers and facilitators perceived by individuals with SCI that participate in high or low levels of physical activity;

- Observe perception changes after a structured physical activity program.

3.2 METHODOLOGY AND RESEARCH DESIGN

3.2.1 Methodology

People with SCI were recruited to identify barriers and facilitators for physical activity. A mixed method analysis was undertaken in two stages incorporating a barriers questionnaire (*Barriers to Physical Activity and Disability Survey - B-PADS*) (Rimmer, 2000; Rimmer, Wang, & Smith, 2008) followed by a one-on-one interview. *Phase One* focused on understanding barriers and facilitators; *Phase Two* consisted of the implementation of physical activity programs in their local gym and observing if perceptions changed post-intervention.

3.2.2 Research design

A cross-sectional design was adopted to obtain quantitative measures via B-PADS on barriers to physical activity (dependent variable) before participating in SCIPA Com (independent variable), a structured physical activity program customised for individuals with SCI according to their physical strengths, personality attributes, and goals. Self-reported physical activity levels were also measured at the same time using the *Physical Activity Recall Assessment for Individuals with SCI* (PARA-SCI) (Latimer et al., 2006j).

Additionally, a qualitative component was carried out on two occasions: before and after intervention, where exercise professionals delivered physical activity programs for people with SCI in community fitness centres. One-on-one interviews were conducted and thematically analysed to uncover the main barriers and facilitators that influence physical activity participation.

The Human Research Ethics Committee of Curtin University approved this study (approval number PT0190/2011). All participants were informed of the procedures and study details prior to obtaining their consent. Participation was voluntary and participants were entitled to withdraw at any moment without prejudice.

3.3 PARTICIPANTS

Individuals with SCI from three states in Australia (Western Australia, Victoria, and Queensland) and one city in New Zealand (Christchurch) were informed of the study through advertisements circulated by SCI organisations and networks, physiotherapists' and social workers' referrals, and through a snowball sampling method (Arcury & Quandt, 1999). Participants were required to contact the researchers for screening and inclusion in the study.

The cohort included two main categories of individuals with SCI defined by whether self-reported baseline status was physically active (≥ 2.5 hours of moderate and/or vigorous-intensity aerobic physical activity per week) or inactive (< 2.5 hours of moderate and/or vigorous-intensity aerobic physical activity per week) (Buchner et al., 2008; Haskell et al., 2007).

3.3.1 Individuals with SCI

Subjects were included if they:

- had a spinal cord injury for more than one year;
- had intact cognitive function;
- were aged between 18 and 80 years of age;
- were community dwelling;
- capable of executing active movements; and
- received medical approval to engage in physical activity.

Both traumatic and non-traumatic causes of spinal cord injuries were included as the clinical signs, symptoms and general therapeutic principles apply equally (McDonald & Sadowsky, 2002). Completeness or incompleteness of SCI were not considered an impediment.

Individuals were excluded if they:

- had full recovery of movement and function post-injury;
- resided in hospitals or care and rehabilitation facilities; or
- were unable to perform active physical activity in fitness centres due to either medical contraindications or a self-reported SCI classification of AIS

(ASIA Impairment Scale) score A (complete) C4 or above according to the *International Standards for Classification of Spinal Cord Injury*, developed by the Neurological Standards Committee of the American Spinal Injury Association (ASIA) (Kirshblum et al., 2011).

3.4 PROCEDURES

3.4.1 Stage 1. Before participating in the SCIPA Com program

Participants were informed of the voluntary nature of *Study 1* before consenting to their participation. They were required to read an information sheet which entailed a description of SCIPA Com, objectives and procedures (**Appendix 1. Information Sheet and Consent Form**). Those interested in participating in the study were given the opportunity to ask questions and signed the consent form in order to be included in *Study 1*.

Demographic characteristics (gender, age, and weight) as well as cause of SCI, AIS classification, years since SCI, use of assistive technology, and physical activity levels were collected at baseline. The PARA-SCI (Latimer et al., 2006j) was used to determine the average time (in minutes) individuals with SCI engaged in LTPA per day. Subjects were classified according to their participation in physical activity, being active or inactive at baseline according to recommendations established by the *2008 Physical Activity Guidelines for Americans* for people with disabilities in order to promote and maintain health (Buchner et al., 2008).

Subjects were required to complete the B-PADS at baseline. The outcomes were used to draw a parallel between the information obtained via questionnaire and through one-on-one interviews also conducted at baseline. Similarities and/or disagreements were analysed between the quantitative and qualitative approaches. The interview was carried out in two different time periods (with a three month period in between assessments) to improve understanding on barriers and facilitators, as well as if a structured physical activity program modified perceptions.

In this study (*Study 1*), we identified and addressed accessibility issues towards physical activity participation (location, transportation, costs and assistance) according to the information obtained via B-PADS and semi-structured interviews at baseline. Between November 2011 and November 2013, SCIPA Com offered an accredited educational program for exercise professionals to work with people with

SCI. The national exercise professional register bodies *Fitness Australia*[®] and *Register of Exercise Professionals* (New Zealand) provided, respectively, 15 and 20 continuing education credit points upon completion of the *Train the Trainers Spinal Cord Injury program*[®] (*T3-SCI*[®]); these points are more than half of the amount needed to meet re-registration requirements every two years. This course was delivered either online or in class attendance and required an average of 10 hours to complete. The content covered basic concepts of neuroanatomy, physical activity for people with SCI, and safety considerations. Further details regarding *T3-SCI*[®] are covered in **Chapter 4, Section 4.2** (Methodology and Research Design).

Exercise professionals were assigned clients with SCI and received ongoing support to design and execute a personalised physical activity program for a minimum of eight to a maximum of twelve weeks; this flexible time-period was necessary to suit different schedules and budgets for training among participants. These programs were reviewed by physiotherapists with extensive experience in SCI rehabilitation and solutions for barriers were discussed. Discounted rates for gym access and exercise professional supervision were negotiated individually with each participating site and paid for by SCIPA Com. The installation of ramps or purchase of small equipment (e.g. lifting hooks and Therabands[®]) were further provided to facilitate access.

Once the physical activity programs were approved by all parties, clients with SCI completed at least two or more supervised training sessions per week with the assistance of a designated exercise professional. The SCIPA Com model and outcomes associated to the effectiveness of the program (i.e. measures of LTPA, quality of life, functional satisfaction, and self-esteem) are covered in **Chapter 4** (*Study 2*).

3.4.2 Stage 2. After participating in the SCIPA Com program

Following the eight-to-twelve week SCIPA Com program, study participants were contacted for a second time and asked the same semi-structured interview questions completed at baseline with the addition of two topics: their experience in the SCIPA Com program; and ability to perform physical activity independently after receiving instructions from exercise professionals. The flow diagram demonstrating the phases of SCIPA Com, sample size and attrition values is presented in **Figure 3.1** (Moher et al., 2010).

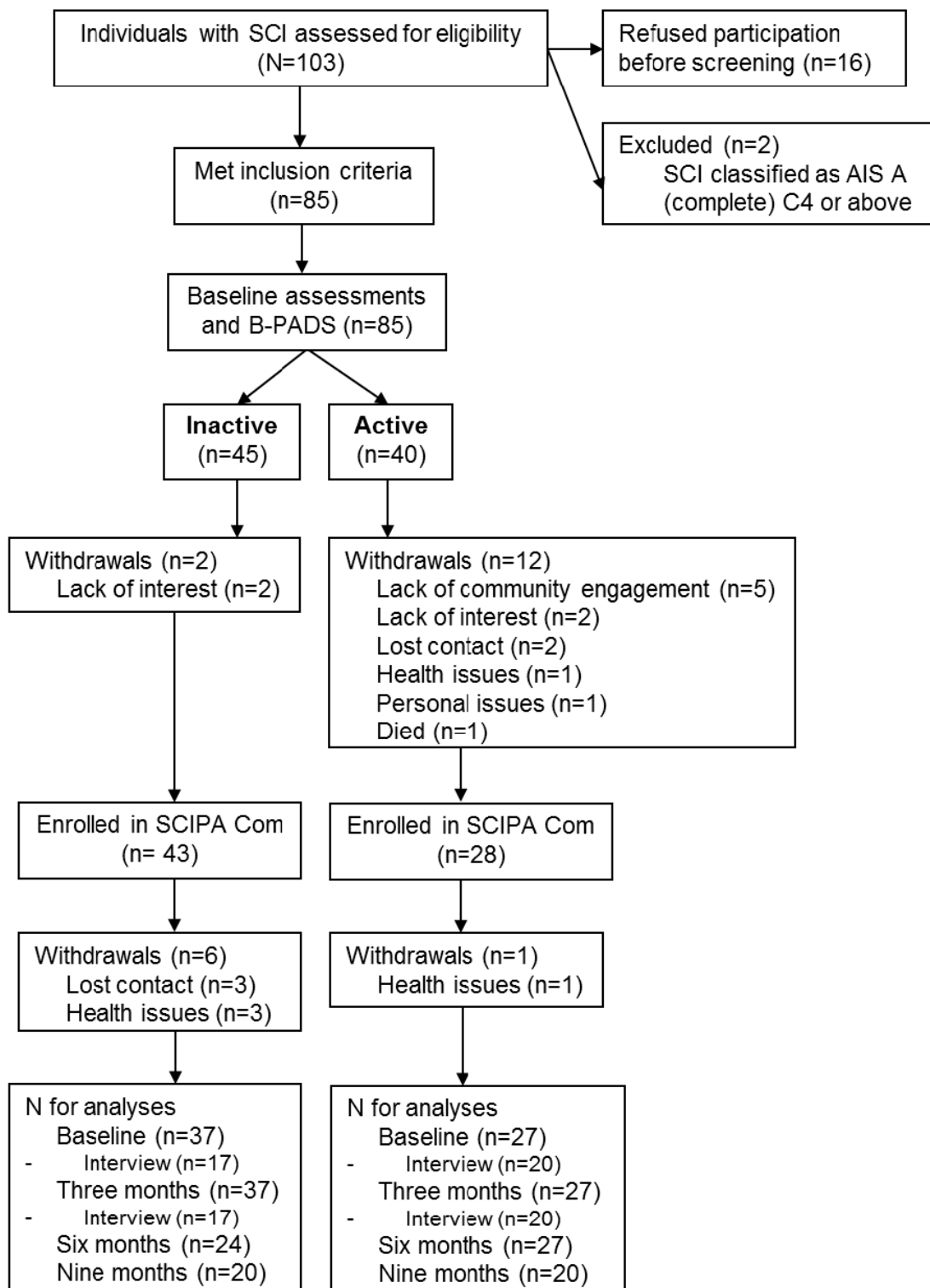


Figure 3.1. The Consolidated Standards of Reporting Trails (The CONSORT Group) flow chart of SCIPA Com. Abbreviations: SCI (spinal cord injury), SCIPA Com (Spinal Cord Injury and Physical Activity in the Community program). Note: The numbers for the nine months follow-up were date censored. The reduction in numbers was related to the fact that the study ceased prior to the nine months follow-up period of the remaining 21 participants, and not due to dropouts.

3.5 MEASURES

Perceptions towards barriers to physical activity were measured through B-PADS (**Appendix 2. Barriers to Physical Activity and Disability Survey**) and changes regarding barriers and facilitators were explored following a semi-structured interview used in two previous qualitative studies (**Appendix 3. Study 1 Interview Questions**) (Kehn & Kroll, 2009; Levins et al., 2004)

3.5.1 Barriers to Physical Activity and Disability Survey (B-PADS)

This 34-item self-reported questionnaire assessed the extent to which participants identified barriers to physical activity (Rimmer et al., 2008). Thirty one items required 'yes' or 'no' answers and the five remaining questions were open-ended and related to: health problems that stopped them from doing physical activity; injuries that precluded their participation in physical activity; past experiences in community fitness centres; concerns about exercising in community fitness centres such as the YMCA; and if there were any other reasons that could impede physical activity participation. The questionnaire was administered by trained researchers in person or via telephone calls and required approximately 10 to 20 minutes to complete. The original 31 categorical items in the B-PADS were found to have strong test-retest (Cohen κ of 0.76) and inter-rater reliability (Cohen κ of 0.86) (Rimmer et al., 2008).

3.5.2 Semi-structured interview

Ten interview questions derived from Kehn and Kroll (2009) and Levins et al. (2004) studies were used as the basis of discussions. Their semi-structured interview guide was one of the most comprehensive set of open-ended questions available at the time of this study targeting SCI populations. The semi-structured interview questions focused on: experiences with physical activity before injury; experiences with physical activity after injury; experiences during rehabilitation; perceived benefits of physical activity; perceived impact of physical activity on secondary conditions; barriers and facilitators of physical activity; and future plans for physical activity. Conversations were digitally recorded with the use of a stereo IC recorder (Sony ICD-UX533F). The duration of recordings varied from 10 to 40 minutes. These were transcribed verbatim and subsequently entered into QSR

NVivo 10 (Copyright © QSR International Pty Ltd 2013) for qualitative analysis. This software was utilised to organise quotes from interviews and perform thematic synthesis of the information.

3.6 STATISTICAL AND QUALITATIVE ANALYSIS

Baseline B-PADS scores were calculated indicating the degree to which barriers listed were endorsed by participants with SCI. All items were organised from the most to the least frequently cited barrier and appropriate descriptive statistics (e.g. mean and standard deviation for continuous variables, median and interquartile range for continuous variables with great variation, and percentage for categorical variables) were calculated using STATA/IC 13.1 (StataCorp LP, 2013). Tests for normality and two-tailed significance at alpha level .05 were performed to detect differences between continuous variables of active and inactive groups. Categorical data were compared via chi-square testing for independent samples.

Interview transcriptions were divided into two categories according to participants' physical activity levels. Coding and thematic analysis of interviews with active and inactive groups were completed separately on QSR NVivo 10 (QSR International Pty Ltd, 2013). I (B.I.R.D.O) systematically reviewed the transcripts to uncover emergent codes across multiple participants in each group to reveal the main barriers and facilitators to physical activity. A second coder (J.G.Z) analysed one sub-group of participants to ensure consistency and agreement between codes. Data were collected until research questions were answered with a wealth of information and when new information was no longer generated (O'Reilly & Parker, 2013). Thematic synthesis was performed and presented in a table to facilitate transferability and generalisation of results. A summary of the findings was reviewed by an academic (A.M.) with extensive experience in qualitative analysis for confirmation of accuracy.

3.7 RESULTS

A total of 103 people with SCI were contacted to participate in our assessments. Eighty-five were screened and met the inclusion criteria to complete the B-PADS at baseline. Eighteen individuals were not included in the study for either failing to meet the inclusion criteria (n=2) or deciding to not partake in assessments (n=16). The demographic characteristics of participants included in this portion of the study (N=85) are presented on **Table 3.1**. Active and inactive groups were significantly different in two items: gender and physical activity levels.

Table 3.1. Baseline demographic characteristics of participants with SCI (N=85) that answered the B-PADS.

	Total (N=85)	Active (n=40)	Inactive (n=45)	P value
Total participants (%)	100	47	53	
Gender (%)				
Male	69	80	60	
Female	31	20	40	.046*
Age (y)	46.92 ± 13.94	46.75 ± 14.03	47.07 ± 14.01	.918
Body weight (kg)	79.82 ± 18.47	79.59 ± 17.2	80.03 ± 19.32	.912
Cause (%)				
Traumatic	84.7	87.5	82.2	
Non-traumatic	15.3	12.5	17.8	.500
SCI Classification (%)				
Tetraplegia, complete	16.5	15	17.8	
Tetraplegia, incomplete	28.2	22.5	33.3	
Paraplegia, complete	28.2	25	31.1	
Paraplegia, incomplete	27.1	37.5	17.8	.230
Years since SCI (y)	8(2-19)	6(2-19)	9(2-19)	.910
Assistive technology (%)				
Manual wheelchair	77.7	80	73.3	
Electric wheelchair	12.9	5	20	
Crutches, cane, walker	5.9	10	4.4	
None	3.5	5	2.2	.160
LTPA (hrs/week)	2.5(0-5)	5.75(3.75-8)	0(0-2)	.001#

Note. These figures reflect within-group frequencies and are not cumulative across rows. Values expressed as %, mean ± SD, or median (IQR). * Significant differences between active and inactive groups ($p < 0.05$) independent t-test (continuous) and Chi square test (categorical). # Significant differences between active and inactive groups ($p < 0.05$) Mann-Whitney U.

3.7.1 Barriers to Physical Activity and Disability Survey (B-PADS)

According to B-PADS, 47% of participants were highly active although 98% of individuals in the inactive group expressed interest in becoming active. **Table 3.2** presents 17 items listed on B-PADS and the respective proportion of participants that considered them barriers. Only 'being injured from exercising' was significantly higher in the active group, which reflects an exposure risk.

3.7.2 Semi-structured interview on barriers and facilitators to physical activity

Sixty-four individuals with SCI completed the SCIPA Com program (See **Chapter 4**) and 37 individuals from this pool were selected to complete two interview sessions about barriers and facilitators to physical activity: before and after participation in the SCIPA Com program. They were chosen according to their baseline activity participation (active or inactive) and SCI characteristics (level of injury and completeness) to form a representative sample of the full range of the cohort studied. Demographic characteristics of these sub-groups are presented on **Table 3.3**. There were significant differences between groups for two characteristics, namely years since injury and, as expected, activity level.

Participants were interviewed about their previous experience with sports and physical activity, rehabilitation, and other topics related to health benefits, barriers, facilitators and experience in SCIPA Com. Quotes (*in italics*) from participants are included to illustrate their perceptions and ideas on the correlates to physical activity. The coding manual comprising themes and examples of quotes from participants can be found in **Appendix 4**.

A summary of the barriers and facilitators to physical activity determined by both B-PADS and thematic analysis is displayed on **Table 3.4**.

Table 3.2. Perceived barriers to physical activity via the Barriers to Physical Activity and Disability Survey (B-PADS).

<i>Values represented in percentages</i>	Total	Active	Inactive	P <i>value</i>
	(N=85)	(n=40)	(n=45)	
	Yes %	Yes %	Yes %	
Have you ever participated in a physical activity program?	98	98	98	.933
Would you like to begin an exercise program?	99	100	98	.343
Did you ever have any health problems that caused you to stop exercising?	38	38	38	.979
Have you ever been injured from exercising?	42	55	31	.026*
I have gone to a fitness centre, but it was not a positive experience.	20	18	22	.587
Do you know of a fitness centre that you could get to?	89	85	93	.213
6a. IF "Yes" Would you have a means of transportation to get there?	96	100	93	.096
6b. IF "Yes" Would you have to pay to be transported to the exercise facility?	34	28	40	.225
6c. IF "Yes" Could you afford to spend this amount of money?	89	95	84	.114
Would you have any concerns about exercising in a facility like a YMCA or community gyms?	21	15	27	.189
Do you feel that an exercise professional would know how to set up an exercise program to meet your needs?	71	75	67	.400
Do you feel that an exercise program could help you?	99	100	98	.343
Has your doctor ever told you to exercise?	32	30	33	.742
Family responsibilities prevent me from exercising as much as I would like	18	23	13	.268
My job prevents me from exercising as much as I would like	21	25	18	.416
Are you ever afraid to leave your home?	9	8	11	.569

Note. These figures reflect within-group frequencies and are not cumulative across rows. * Significant differences between active and inactive groups ($p < 0.05$) Chi square test.

Table 3.3. Baseline demographic characteristics of a subset of participants with SCI (n=37) who also participated in one-on-one interviews regarding barriers and facilitators for physical activity.

	All (N=37)	Active (n=20)	Inactive (n=17)	P value
Gender (%)				
Male	70.3	75	64.7	
Female	29.7	25	35.3	.495
Age (y)	46.56 ± 12.6	47.95 ± 12.58	44.94 ± 12.81	.477
Body Weight (kg)	80.91 ± 21.54	86.42 ± 25.58	74.44 ± 13.59	.092
Cause (%)				
<i>Traumatic</i>	89.2	95	82.4	
<i>Non-Traumatic</i>	10.8	5	17.6	.217
SCI Classification (%)				
<i>Tetraplegia, complete</i>	18.9	15	23.5	
<i>Tetraplegia, incomplete</i>	35.1	40	23.5	
<i>Paraplegia, complete</i>	24.3	25	23.5	
<i>Paraplegia, incomplete</i>	21.6	20	29.5	.871
Years since SCI (y)	10(2-19.5)	4.5(2-15)	19(9-29)	.017 [#]
Assistive Technology (%)				
<i>Manual Wheelchair</i>	70.3	70	70.6	
<i>Electric Wheelchair</i>	13.5	10	17.7	
<i>Crutches, Cane</i>	10.8	15	5.9	
<i>None</i>	5.4	5	5.9	.773
LTPA Level (hrs/week)	3.1(0-5)	4.5(3.3-6.75)	0(0-0)	.001 [#]

Note. These figures reflect within-group frequencies and are not cumulative across rows. Values expressed as %, mean ± SD, or median (IQR). [#] Significant differences between active and inactive groups (p<0.05) Mann-Whitney U.

Table 3.4. Prevalence of barriers and facilitators among individuals with SCI: Results from B-PADS and thematic analysis.

B-PADS (N=85)		Themes (N=37)											
Barriers	Active (n=40) %(n)		Inactive (n=45) %(n)		Active (n=20) %(n)		Inactive (n=17) %(n)		Active (n=20) %(n)		Inactive (n=17) %(n)		
	Baseline	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	
Cost of the exercise program	48(19)	44(20)	Financial	25(5)	35(7)	41(7)	18(3)	Financial assistance	10(2)	20(4)	-	29(5)	
Lack of accessibility	40(16)	44(20)	Accessibility barriers	15(3)	45(9)	59(10)	59(10)	Accessibility facilitators	30(6)	30(6)	47(8)	35(6)	
Lack of motivation	25(10)	44(20)	Lack of motivation	20(4)	15(3)	29(5)	12(2)	Intrinsic motivation	40(8)	20(4)	29(5)	24(4)	
Lack of energy	43(17)	27(12)	Lack of energy	30(6)	15(3)	-	-	-	-	-	-	-	
Lack of time	38(15)	24(11)	Social barriers	30(6)	30(5)	18(3)	18(3)	Socialisation	20(4)	15(3)	-	18(3)	
Lack of a personal care attendant	28(11)	31(14)	Lack of help from carers or exercise professionals	15(3)	10(2)	29(5)	-	Exercise professional with knowledge in SCI	20(4)	50(10)	41(7)	24(4)	
Pain	30(12)	24(11)	Physical disability	20(4)	35(7)	29(5)	24(4)	Physical ability and fitness	20(4)	-	18(3)	12(2)	
Incontinence	28(11)	22(10)	Incontinence	10(2)	10(2)	6(1)	-	Programmed bladder and bowel management	10(2)	15(3)	12(2)	6(1)	
Don't know where to exercise	25(10)	22(10)	Information related barriers	35(7)	10(2)	18(3)	24(4)	Information	25(5)	10(2)	-	24(4)	
Feel uncomfortable or self-conscious	18(7)	22(10)	Psychological barriers	30(6)	30(6)	18(3)	12(2)	Mental well-being	20(4)	45(9)	-	24(4)	
Lack of interest	23(8)	13(6)	-	-	-	-	-	Interest in physical activity	20(4)	15(3)	-	-	
Exercising is boring or monotonous	15(6)	20(9)	-	-	-	-	-	Advertising and sports tryout events	10(2)	10(2)	-	29(5)	
Don't know how to exercise	13(5)	22(10)	-	-	-	-	-	Knowledge on how to exercise	25(5)	10(2)	-	24(4)	
Health concerns	13(5)	20(9)	Secondary health problems	40(8)	40(8)	29(5)	53(9)	-	-	-	-	-	
Lack of transportation	18(7)	13(6)	Lack of transportation	25(5)	-	-	29(5)	Efficient public transportation system or private vehicle	25(5)	-	-	29(5)	
Exercising is too difficult	8(3)	9(4)	-	-	-	-	-	-	-	-	-	-	
Lack of support from friends and family	3(1)	13(6)	-	-	-	-	-	Support from family and friends	15(3)	15(3)	-	-	
			Bad weather conditions	15(3)	25(5)	12(2)	-	Good weather conditions	15(3)	15(3)	12(2)	24(4)	
								Community health program for people with SCI	5(1)	10(2)	29(5)	24(4)	
								Structured physical activity programs	-	15(3)	18(3)	24(4)	

Note. No statistical differences were found between active and inactive groups according to B-PADS (p values > 0.5).

Physical activity experience prior to and after SCI

As anticipated, those in the active group demonstrated greater participation in sports and physical activity before and after their SCI compared with those who were less active prior to their injury. The main pre-injury activities cited were swimming, fitness training, cycling, running and walking, along with popular sports such as football (Australian rules), basketball, and tennis. Following the SCI, the most popular activities trialled by this cohort were wheelchair basketball and rugby. The main differences between groups were in the multiplicity of activities practiced (i.e. hand cycling, track and field, archery, skiing, surfing, etc.) within a variety of environments (i.e. outdoors, courts, and pools) by highly active individuals.

Rehabilitation experience following SCI

A combination of positive and negative perceptions about their rehabilitation program following SCI was reported by participants. Psychological and practical difficulties surrounding adaptations to their condition challenged physical activity expectations, though the majority acknowledged the benefits and importance of health care. Among the positive aspects, education on activities of daily living (ADLs) and physical exercises were considered vital for future self-management.

... I felt comfortable with them [rehabilitation professionals] and they taught me a lot... I had to put my life back together and also the physical side of it as well ... I learned first of all how to manage myself in a way that I could actually live a proper life... I'm talking about how to dress up, how to get out of bed, how to get on the toilet, how to brush my teeth, how to brush my hair. How to go out to the car, how to transport, how to sit in, sit out of the car, how to transfer to a chair, how to get on the couch, I can go on and on. (Active, male, 38, T10 complete)

In contrast, many participants from both groups considered rehabilitation insufficient in terms of physical improvements, time available, and further orientation upon discharge from health services. Others recalled insufficient staffing and limited physiotherapy sessions. Another major issue was that the main focus of rehabilitation was on ADLs, failing to emphasise the importance of LTPA.

Comparisons between groups revealed that the active population perceived more physical benefits and were better informed on training options in the

community during the rehabilitation stage. Additionally, peer mentoring programs ensured a stronger presence within the high activity group for information exchange and support.

...it's really good when you have contact with the sports and try them out. Because even though like sometimes you think ah, I'm not really going to like it but then you try it. I've tried some of the wheelchair sports as well and I love them. (Active, male, 44, T6-7 Complete)

Information on benefits of physical activity

All participants associated physical activity to corporeal, psychological and social benefits. Enhanced fitness, prevention of secondary complications (e.g. pressure ulcers, urinary tract infections, and diabetes), and weight management were commonly mentioned. General psychological well-being was attributed to improved self-esteem and social integration. Active individuals had increased awareness of the physical and psychological benefits that stem from activity participation. Improvements were reported on energy levels and physiological functions (musculoskeletal, cardiovascular, respiratory, immune, and gastrointestinal). They were also attentive to detrimental effects, such as increased spasms triggered by physical activity.

By doing the gym I find myself being a lot fitter, which helps with my positive outlook on things and my attitude to things can be a lot better. Generalised exercise helps with keeping my body in an order that it needs to be. Bathroom antics don't usually come into play too often once I've been doing it for a period of time. I find that if I've been laid up for any length of time that my body gets very lax and doesn't like to - wants to do its own thing, but when I've been exercising it tends to pull it back into order and keeps things going. I feel good about myself when I go, when I'm there. (Active, male, 42, C6-7 Complete)

... with the grinding motion [of the wheelchair] I was using one particular muscle group. It's getting that muscle balance back into my body and so you're getting a balanced body instead of just developing one set of muscles. Also getting out into the sunshine and pushing around a lot more. Getting a bit more vitamin D and just physical exercise full stop is generally just good for your blood flow and your bowels as well and bladder. Because you're - if you're sitting stationary all day it just all sits there, whereas if you're moving around, especially for bowel motions, it makes that a lot smoother. I found anyway. (Inactive, male, 43, C4-5)

Benefits mentioned at baseline were reiterated during follow-up interviews and additional improvements were perceived among the previously inactive group. Positive reports concerning better breathing and functionality were added, as well as increased motivation. The active group continued to demonstrate a better level of awareness of health benefits compared to the inactive group, though improvements were noticeable. There was one case of shoulder re-injury due to excessive weight training.

Yeah well obviously the cardiovascular diseases, the exercise definitely benefits your heart and lung capacity. It's also a great benefit for your weight loss or keeping your weight in check. It also improves your circulation especially the cardio type exercises. Weight exercises or strength exercises obviously assist with your muscle tone and strength in certain areas. I mean obviously not to mention the - getting the endorphins flowing and improving your mental state as well so that's a big bonus. (Previously inactive, male, 34, C6 Complete)

It helps with my bowels and my digestion because I have slow digestion from stomach to intestines and when I exercise it moves faster. I also find that I get less bone pain... Because I have weak muscles in my stomach the muscles in my back get overused and then they start spasming. When I workout my strength in my core muscles, which means my back muscles don't have to work so hard... it means I can sit longer... I can drive now. I used to have a brace for my leg and foot like it is an ankle foot orthotic so I would have smooth walking motions, but I don't need it any more. (Previously inactive, female, 19, T10-L4 Incomplete)

Barriers to physical activity in community health and fitness centres

Initial assessments revealed common barriers among both active and inactive groups with SCI. Their perceptions were influenced by many factors: injury classification; associated comorbidities; environment inhabited; social support received; mental health; and their financial situation. The following themes summarise the barriers identified before and after participation in SCIPA Com.

Accessibility barriers. Prior to participation in SCIPA Com, facility access, as well as adapted equipment and efficient transportation were the general main concerns, especially among the inactive group. The lack of, or noncompliance with, policies and procedures both in fitness facilities and the community resulted in environmental barriers. Participants believed fitness centres would not have equipment for wheelchair users or be structured for ease of manoeuvring in between apparatus. Others were discouraged by employees of fitness centres being unfamiliar with adapted training and safety procedures for the SCI population.

I know in the past I've actually rang a gym that's very close to my home and asked them if it was accessible. Or if it was - like the sports equipment were - like for example if you could move the bench and so someone in a wheelchair could use say a pull-down pulley thing. They said no, they can't do that. Although it was accessible to get into the gym, it just didn't facilitate - so I sort of gave up straightaway. I'm thinking a lot of the gyms are going to be similar sort of thing.

(Inactive, female, 40, T7-10 Complete)

[Lack of] greater availability of resources. For example, people that I know are unable to do any training anymore. After their rehab had finished that was it, and a lot of gymnasiums would not take them on, or personal trainers. (Active, male, 55,

T10 Complete)

Following the training program, participants considered fitness centres architecturally accessible. Interestingly, more attention was given to inaccessible gym equipment. Handles, bars and dumbbells were often placed at unreachable heights for those on wheelchairs and transfers onto equipment seats were generally avoided by clients to ensure safety and unnecessary effort.

I can't get on any machines. I can only do free weights. Thank god for [the exercise professional], she came up with some brilliant ideas. Cable machine is the only thing I can get on, but bench pressing and lat pull downs and stuff like that, that is impossible. Because the gym is not made for people in wheelchairs unfortunately. There is - I could do everything pretty much, but as I said, it's thanks to [the exercise professional] because she came up with the whole range of exercises. (Active, male, 38, T10 Complete)

Well a bit barrier for the physical activity that I've encountered is obviously the - is more the access to personal trainers and/or appropriate equipment, that ideally you'd be able to utilise equipment fairly independently. But the big thing I've found that is the big restriction is not being able to find equipment that's appropriate I guess or easy to use or to be able to use independently. Up until now, it's all having to rely on a personal trainer or a gym instructor to assist and set up and so forth. (Previously inactive, male, 34, C6 Complete)

Secondary health problems and physical disability. Initially, secondary health problems were one of the central barriers to activity among both active and inactive groups. Spasticity, pressure ulcers, incontinence, urinary tract infections, pain, orthopaedic injuries, autonomic dysreflexia, and physical limitations curtailed their ability to engage in sports or use certain equipment. Lack of fitness itself and reduced energy levels were reported as barriers for the inactive group as well.

Fatigue, no strength in the legs to actually carry me, the back injury is quite severe and any running or pounding does sort of reverberate through the body. So it's very difficult to get any sort of speed up. So you know physical activity like that is quite difficult. (Active, male, 52, C7-T1 Incomplete)

See at the moment, I'm not strong enough. I can get myself across the road but I'm not strong enough to get myself up the hill on the way back. I have to get assistance because the hill is too steep. (Inactive, male, 38, T10 Complete)

In the post-training phase, secondary health problems remained the second most prevalent barrier reported by both groups. Infections and being generally unwell were the main causes of nonattendance.

A general feeling of unwell... There are days when the body just tended to shut down and I physically and emotionally couldn't be physical for want of a better word yeah. (Active, male, 52, C7-T1 Incomplete)

Financial barriers. Financial constraint was a significant barrier, particularly within the inactive population. SCI often prevents people from resuming their pre-injury work activities and/or limit them to a disability pension. Investment in sporting equipment, memberships for fitness centres and expenses for private exercise professionals were deemed secondary to living and medical costs. Prices of physical activity programs varied according to each fitness centres policies regarding discounts for clients with disabilities and the fees established for personal training. Monthly gym memberships ranged from \$25 AUD to \$150 AUD. Most exercise professionals agreed to participate in SCIPA without honorarium, though those that earned income exclusively on the basis of personal training fees were compensated \$25 to \$30 AUD per session.

Well, the main one would be ongoing cost expense, being on [a fairly small] pension, and then you add anything in that costs. (Inactive, male, 50, C5-6 Incomplete)

Disability pensions in Australia are currently \$766 AUD per fortnight (Department of Human Services of the Australian Government, 2014), which constrains many participants from hiring exercise professionals on an individual basis. After SCIPA Com, the majority of participants expressed the intention of purchasing another gym membership, though they remained conscious of the financial impracticality of employing exercise professionals privately.

The need to have another person there to help with the exercise regime and then the cost of joining the - you know, doing the activities, joining the gym and then also the cost of getting to and from home to the gym. So it's quite a costly exercise in getting into a car when you're paying oh, like it's only sort of like 10 bucks each way but then if you include gym on top of that, when you're only on a pension it's quite a big portion of it. (Previously inactive, male, 50, C5-6 Complete)

Information related barriers. Baseline interviews indicated lack of information on physical activity programs tailored for people with disabilities in the community. Participants believed there was no public support to integrate the SCI population in physical activity, nor efforts to prepare the community for their needs. Participants also relied on assistance to execute activities properly but feared exercise professionals were not prepared to develop safe physical activity programs.

Lack of knowledge, I suppose, with what can I do or how can I do it? Or what kind of machine could I use for? (Active, male, 41, T4-5 Complete)

... there's an expectation of a trainer or something of a physio person doing things beyond what they believe they're capable of. So it's that gap I think between I suppose a confidence that what people are teaching you or working with them to do is actually right for them. (Active, male, 54, C5-6 Incomplete)

Though confidence in exercise professionals increased after SCIPA Com, both groups specified once again the lack of public health initiatives and scarce information on the programs that may be available in the community.

One of our biggest issues is we just don't know what's out there. Because we live in the community and we don't associate so much with the hospital and people straight out of the hospital, we don't know what's on. A lot of the time, wheelchair sports are - unless you're going chasing them, they're not promoted anywhere. (Active, male, 42, C6-7 complete)

Social barriers. Individuals from both cohorts described common social attitudes that provoked discomfort and frustration. Staring, condescending treatment, fear, and lack of empathy were considered discouraging.

I find I really just have to psyche myself up a bit and go right, I'm going to go to the gym, because you do get stared at a bit... and I don't go when it's busy because you don't want to hold people up with getting in and out of your wheelchair, when you are doing circuits, because they are really quick. You might only be doing 30 seconds or one minute on something and you don't want to hold the queue up.

(Active, female, 37, C6 Incomplete)

Social life also affected time management due to family responsibilities, prolonged work hours, and time required for ADLs. Additionally, commitments with carers and preparation involved with training conflicted with participants' schedules throughout the program.

Yeah, I'd say every day activities and appointments stopped me from getting into any routine, or even establishing any routine. (Inactive, female, 53, C5-6 Incomplete)

Various social commitments persisted as barriers and challenges to time management were presented throughout the program. They were required to account for the time necessary to arrive at fitness centres and arrange the equipment for use, as well as their normal training hours. Furthermore, a couple of fitness centre managers deemed their facilities and expertise inadequate and some health professionals held patients institutionalised within hospitals without presenting options in their community.

*Not so much they weren't accessible but the way that the hospital set it up, or set me up, was kind of like you have to wait for a physio. It makes it seem like that physio is the only option and the only thing that will help you and no one else will understand... they don't actually give you reasons why you can't go to the gym, they just freak out because they think, I don't know, you're going to hit yourself on the head with a dumb bell or something. But they never really put me in a place where it's like a positive way. (**Previously inactive, female, 19, T10-L4 Incomplete**)*

Psychological barriers. Emotional and motivational barriers played a significant role in physical activity participation before SCIPA Com. Issues included self-consciousness, lack of confidence, indifference to sports, dislike for physical exertion, lack of goals, and mental fatigue attributed to the amount of concentration required for functional activities.

*“It's motivation. Motivation is a big thing. Maybe lack of goals and motivation.”
(**Active, male, 44, T6-7 Complete**)*

*“Self –confidence really. Also it is really a thing of just getting used to being in the public again.” (**Inactive, male, 37, T7-10 Incomplete**)*

Active individuals reported more frustration and diminished self-confidence when confronted with the inability to perform activities at pre-injury level. In some circumstances, participants opted only for activities executed independently to avoid embarrassment or distressing assistants.

*Some sports are impossible because of my [lesion] I suppose, having nothing from the hips down probably stops from riding a horse. I see some people, they get strapped onto them, but that wouldn't interest me if you couldn't ride it like it was done before the accident. (**Active, male, 52, T10-11 Complete**)*

There's also the embarrassment thing too. It's just like, they wanted me to try wheelchair rugby, transferring in to - have you ever seen the wheelchair rugby? ...

Somebody's got to try and lift me up and I just don't like being embarrassed. If anything should happen, plus it's trying to get my bowels and bladder under control as well. (Inactive, male, 37, T7-10 Incomplete)

A few participants in the inactive group disclosed feeling depressed and required psychiatric assistance to manage their disorder.

Probably a bit of depression probably, a bit depressed and I can't be bothered, my own demons and the fact that I started out physio and I went really hard and I was going good but I still kept falling backwards and backwards due to my depression and in the end I just thought what's the point when I've done - tried so hard and I've just gone backwards anyway, so I just gave up. (Inactive, male, 37, C5 Incomplete)

Subsequent to the physical activity program, a reduced rate of psychological barriers was reported in both groups. Self-confidence increased, although motivation remained a struggle for many.

I don't always have the motivation to go to the gym. I can't do everything when I get there so sometimes I'm a bit frustrated, like some of the equipment I can't get access to is upstairs or it's not built in a way that I can use it. (Active, male, 46, T3-6 Incomplete)

Weather barriers. Adverse weather conditions were prevalent barriers across groups before SCIPA Com. Rainy days were the main impediment due to potential hazards and difficulties in remaining dry during transfers into vehicles and buildings. Intense heat caused discomfort, fatigue, and dehydration. Finally, colder temperatures affected their motivation to exercise outdoors or swim. Interestingly, more people in the active cohort complained about weather conditions during post-assessments, whereas the previously inactive group no longer mentioned it.

Facilitators to physical activity in community health and fitness centres

Numerous measures are required to adapt the environment and provide financial, physical, psychological, and social support for those living with SCI. Interviews prior to and following SCIPA Com revealed facilitators that decreased sedentary behaviour.

Accessibility facilitators. These ranged from wheelchair accessible centres and equipment to personal assistance. Prior to joining the physical activity program, the inactive population highlighted the importance of health and fitness programs targeted for people with SCI in the community, and their promotion via health care providers.

Having those people around you and the right accessible equipment and facilities essentially. Always with wheelchair rugby we had a couple of other people would come down, our coach and other associated people down there would give you a lift in and out of rugby chairs - because I can't transfer in and out of my day chair - get strapped up and put special gloves on or whatever. So a similar sort of thing would need to be done in a gym environment. To get out of this chair I'd need probably two people to give me a hand. If I was just doing training in my chair I'd need just one person. (Inactive, male, 43, C4-5 Incomplete)

[SCIPA Com] was more about doing a gym program as opposed to some sort of rehabilitative physio [physical therapy]. It was more about a lifestyle option which is a better way to go. To me physio [physical therapy] is like you do something until you get better or you don't get better. But somewhere along the line there's an end point... so this is more something that's got future and that's where huge benefit is. Also tying in with the local community - local provider that's been a huge benefit too. (Previously inactive, female, 53, C5-6 incomplete)

More details on facilitators were provided following SCIPA Com, such as: equipment with removable seats, hand ergometers, open floor space, efficient transportation options, and exercise professionals with education in SCI to guide safe execution of exercises. The previously inactive group attributed great

importance to structured physical activity programs, which acted as catalysts to increase their participation. Constant monitoring and immediate feedback to detect improvements were further listed as facilitators.

Affordability. Subsidy for the acquisition of gym memberships and professional orientation was a paramount necessity. These could be in the form of membership discounts and concession prices provided by community fitness centres, or funding from public and private health insurance companies.

... if it's given cheaper than normal, then that would be nice and helpful, but yeah it's a question of those things - trying to figure out what is going to be the cost and doing it - I suppose the cheaper it is, the more you're probably able to do it, but again it's a little bit of an unknown territory at this stage, because I'm not sure of the cost involved. (Inactive, male, 50, C5-6 Incomplete)

The financial assistance for gym access and travel to and from fitness centres provided by SCIPA Com encouraged most participants to access fitness centres and exercise professionals. SCIPA Com covered gym memberships (\$25 AUD to \$150 per month), personal training fees (\$0 to \$30 AUD per session), lifting equipment for those with reduced hand mobility (\$30 AUD per lifting hook), ramps (\$60 AUD per ramp), and Therabands® (\$10 to \$20 AUD for two meters).

Mental well-being. Motivational and emotional facilitators surfaced in the first interview period. Intrinsic motivation was presented as the main determinant in both groups, improved by goal setting and being held accountable for goals over time.

I'm quite motivated and quite competitive against myself. So if I've got a program and I've got goals that helps me. I think if I had an enthusiastic and encouraging trainer. I think maybe having other people in a group, doing something in a group, is good. (Active, female, 62, C6-7 Incomplete)

The sources of motivation and emotions were different among groups. Active individuals attributed their emotional draw to happiness and interest, whereas the

previously inactive group related it mostly to self-esteem. In the motivational spectrum, competition and perceptible health improvements were stimulating among the active population while the less active group attributed motivation to challenge, discipline, perceived functional improvements, and enhanced body-image.

I think the initiation - good initiation to it and some strong discipline to start off with. I'd need the discipline myself, to sell it to me that this is going to pay off. So that's, I suppose, part of the motivation. Then once - if I started, within the two weeks, it would just fall into a system and I'd be able to negotiate my calendar of events, to slowly incorporate this as a routine, this is something that I do. I'd be really wrapped because that would increase my self-esteem. (Inactive, female, 53, C5-6 Incomplete)

After SCIPA Com, enjoyment and feeling comfortable in the environment were found to be encouraging, along with perceived benefits to functionality and health. The previously inactive group also reported increased self-confidence and motivation due to improvements in their life style.

I think more mentally than physically it helped me because I wasn't comfortable going to the gym prior to this program... So that [SCIPA Com] was just fantastic and the people that were in the gym were nice enough... They were actually quite receptive to someone who was, for want of a better word, gimpy leg walking around in their gym. They didn't mind seeing something like that. (Active, male, 52, C7-T1 Incomplete)

Information on available resources. In addition to more information on benefits and physical activity opportunities, quality of information was further debated. More guidance from health care providers and peer mentors was required especially in the early stages of rehabilitation.

*Yeah, adapted equipment and I think information about the wheelchair sports network, where things have been set up for people in wheelchairs to participate... I think good access is really important. Like I went to a different swimming pool recently and the pool was a really long way away from the change rooms and involved quite a big push. That put me off and I went back to my other swimming pool, because when you are cold and you get out you just want to be able to be - get in and get out. You just want to be able to get back to the change room and get back to your car pretty quickly. It's funny, you are lazy about those aspects, but you are quite happy to go and do the exercise itself. (**Inactive, female, 37, C6 Incomplete**)*

An organised referral system between rehabilitation and community fitness centres would lead to more active life styles.

*We [physiotherapist and patient] had a general talk and they put me on to two program possibilities and one of them was yours [SCIPA Com] which we followed up on and then some time later we started the three month program. So that's what started me off doing it. (**Previously inactive, female, 53, C5-6 Incomplete**)*

*Well first of all you guys [SCIPA Com] - that's what it started with, it's as simple as that. I started, as I started this program then I started back to go back to the gym and I felt - I just felt great every time. Every single time I came out of there, I had the 45 minutes with [the exercise professional] and had a great training session, a lot of cardio. I just felt on top of the world every single time. (**Active, male, 38, T10 Complete**)*

Physical ability. Participants believed that the preservation of muscle control and activation were significant facilitators, especially when one was able to exercise independently. Other factors involved were good fitness levels and energy, healthy nutritional habits and weight, sleeping well, and absence of injuries and pain. Indeed, participants with more control over bodily functions were more likely to engage in physical activity. Lower SCI levels, decreased spasticity, and reduced pain were associated with increased participation post-intervention.

“I just - I've identified what I can do and I enjoy and I'll leave it at that.” (Active, male, 40, C5-6 Incomplete)

Social. Great sources of motivation in the beginning were company from friends or exercise professionals and allocating specific times for physical activity.

I'm just used to playing team sports. I've never been one to just go to the gym by myself and work out by myself. I just find it boring but if I went to the gym with a couple of mates and all of that and we were together, then I'd do it. I know some people can just go to the gym and work out by themselves but I just get bored and I go too easy myself. (Inactive, male, 37, C5 Incomplete)

Later on, both groups attributed importance to community participation. Positive rapport between participants, exercise professionals and gym members resulted in high attendance rates.

Probably I could say also the fact that starting the program you had a personal trainer who was there to work with you to what exercises I could do. I don't know whether they're all the same but mine is very encouraging, very motivated and she spurs you on and she's chatty as well so that all helps. It's just encouraging. It's not off putting at all to go there. (Previously inactive, female, 53, C5-6 Incomplete)

Well, I think having been in this program has been great. Because having a personal trainer and a time really does make you go, because you're making that commitment and you don't want to let somebody down. (Active, female, 37, C6 Incomplete)

SCIPA helped me with as well. It made me look at the gym and say it's not just a death sentence from me being in a chair, it helped me a lot to get my confidence up and meet new people. Which helps me want to do more exercising and stuff too. (Previously inactive, male, 37, T7-10 Incomplete)

Good weather conditions. Mild climates and lack of rain favoured performance and attendance to training sessions among individuals with SCI.

Over the winter it is always harder because I can't go out in the cold, in the winter. Summer I do it a lot more; I'll end up going out probably about three or four times a week for at least an hour-and-a-half each time. (Active, male, 42, C6-7 Complete)

Plans for future physical activity after SCIPA Com participation

Following SCIPA Com, participants were uncertain on how to fund their activities though they expressed interest in continuing their training.

Structured physical activity training with a proper instructor and a proper program, that's what I've been doing and I plan to keep up for as long as I possibly can... because that will only assist me in all aspects of my life, were it be from transferring to pushing, rolling over in bed, simply things like brushing my teeth. All sorts of areas, you know, keeping the strength and my upper body strength up assists me in all my daily living activities.

(Previously inactive, male, 38, T10 Complete)

We're actually looking to see - I think the group of us that are going to [exercise professional], want to continue and obviously there is no more funding from SCIPA, so we are investigating other - and as [exercise professional] is as well, investigating other options for funding. **(Previously inactive, male, 34, C6 Complete)**

3.8 DISCUSSION

As demonstrated by previous researchers, public health initiatives such as SCIPA Com were effective in assisting populations at high risk of physical inactivity, especially those with SCI (Rimmer & Henley, 2013; Rimmer & Marques, 2012). Resembling Canadian and North American rates, less than half of participants in this study were physically active at baseline (Martin Ginis et al., 2010e; Scelza et al., 2005). Therefore, determining whether a community-based physical activity program reduced barriers and facilitated physical activity among active and inactive individuals with SCI was the main objective of this study. The first step entailed understanding barriers and facilitators better; followed by the implementation of physical activity programs in their local gym. To the best of our knowledge, this is the first study to explore perceptions towards physical activity before and after a structured physical activity program for individuals with SCI. Findings on barriers to physical activity corroborated with similar studies (Kehn & Kroll, 2009; Rimmer, 2000; Scelza et al., 2005) and produced results comparable to those that analysed the effects of exercise programs (Block et al., 2010; Froehlich-Grobe et al., 2014; Gainforth et al., 2014; Pelletier, 2014; Wise et al., 2009).

Ordered from most to the least frequently cited barrier on B-PADS assessments, the main issues encountered were costs, accessibility difficulties, social commitments, lack of motivation, low energy levels, and lack of assistance for physical activity. The same concerns were reported by Scelza et al. (2005). Their study detected motivational problems as the most prevalent barrier in individuals with SCI (54.2%), followed by lack of energy (41.7%), costs (40.3%), and insufficient knowledge on where to exercise (36.1%); 44.4% also believed exercise professionals would not know how to properly assist them. Although another survey involved African American women with different diagnoses and mobility impairments (e.g. arthritis, stroke, multiple sclerosis, etc.), similar barriers were found (Rimmer, 2000). The only difference in the aforementioned study was the emphasis attributed to transportation issues (61%) and not knowing where to exercise (58%).

Differences pertaining to transportation can be explained by the elevated socioeconomic status of our study's cohort. As verified by Rimmer et al. (2008), stroke patients with higher income were less likely to indicate transportation as a problem. Not knowing where to exercise was also not problematic for the present sample because SCIPA Com was responsible for organising community fitness

centres for participants. All aforementioned studies revealed that primary health care providers did not recommend physical activity to over half of their patients. Researchers have emphasised the need for improvements in conveying information and opportunities on physical activity (Kehn & Kroll, 2009; Pelletier, 2014; Rimmer & Marques, 2012; Scelza et al., 2005; Vissers et al., 2008). This is especially important during the rehabilitation period, when patients with SCI have more exposure to health professionals (Vissers et al., 2008) .

The present cohort revealed more interest in becoming physically active in relation to other studies (Rimmer, 2000; Scelza et al., 2005), possibly due to the prospect of being involved in SCIPA Com. Along with interest, the main facilitators for physical activity were intrinsic motivation, accessibility, assistance from exercise professionals, financial support, and mental well-being. Physically active individuals with SCI from a study by Kehn and Kroll (2009) were stimulated by similar facilitators in addition to health concerns (weight management and disease prevention). A recent meta-synthesis on barriers and facilitators corroborated findings and further highlighted the importance of a physically active identity and restitution of a personal narrative among individuals with SCI (Williams, Smith, & Papatomas, 2014). Jaarsma et al. (2014) also detected social contact and enjoyment as important incentives for sports participation.

Regarding between-group (i.e. active versus inactive) comparisons, B-PADS scores were only statistically different for one theme: 'being injured from exercising'. The rate was higher in the active group possibly due to more interest and exposure to sports and physical activity (Fullerton et al., 2003). Considerable differences between the two cohorts were also observed in four other categories favouring active individuals: increased motivation, energy, time, and knowledge on how to exercise. Likewise, a review on correlates and determinants for physical activity among people with SCI verified a direct positive correlation between these four factors and high physical activity levels (Fekete & Rauch, 2012). The in-depth qualitative analysis conducted before and after SCIPA Com corroborated the barriers and facilitators described in literature (Kehn & Kroll, 2009; Vissers et al., 2008) and revealed details on the following issues: accessibility, physical, psychological, social, and financial barriers.

Accessibility issues

Accessibility has been an issue in all studies on barriers for individuals with SCI due to inadequate infrastructure and equipment, and lack of assistance (Kehn & Kroll, 2009; Levins et al., 2004; Scelza et al., 2005; Vissers et al., 2008). The participating community fitness centres in SCIPA Com agreed to and fully supported their employees' training. Exercise professionals were motivated to learn more about adapted training and to expand their ability to work with the SCI clientele. Their presence and guidance impacted participants positively, as verified by Froehlich-Grobe et al. (2014). Their experiment observed that groups supported by staff members displayed a moderate increase in physical activity levels and frequency when compared to the self-monitored group. Wise et al. (2009) further encouraged increased audiovisual guidance for home-based exercise programs, though they did not encounter significant differences between supervised and unsupervised groups.

Physical issues

In the physical domain, participants did not expect the same outcomes as their able bodied counterparts. They were aware of the increased difficulties in reducing weight or improving cardiovascular and metabolic functions, as did participants in earlier studies (Kehn & Kroll, 2009). Various other perceptions towards physical activity shifted after exposure to SCIPA Com. Fewer barriers were listed and more facilitators were perceived especially among the previously inactive group. Among those considered previously inactive, motivation, costs, assistance, and weather were less of an impediment following the program. Participants were also able to associate more health benefits to physical activity. Their reports on improved physical fitness and strength, as well as benefits associated to mental wellbeing is strongly supported by evidence (Martin Ginis et al., 2012g; van Leeuwen et al., 2012f).

Issues pertaining to transportation, lack of information and secondary health problems were brought to the attention of individuals in the inactive group during the second assessment. Transportation had consistently been reported as a difficulty among other studies (Jaarsma et al., 2014; Kehn & Kroll, 2009; Rimmer, 2000), and was in fact troublesome for those that relied on family members or taxis to transport them to the fitness facilities. A recent study involving 180 individuals with SCI highlighted this difference between perceived barriers and real barriers (Cowan et

al., 2013). The five most prevalent barriers were lack of energy, motivation, and time; not knowing where to exercise and costs associated to training, though their population revealed a higher proportion of individuals self-reported as exercisers (approximately 64%). In this study's sub-analysis comparing active and inactive individuals, barriers perceived by non-exercisers were slightly different. Some believed that exercise would make their condition worse, was too difficult, and/or was not interesting; whereas others did not know how to exercise.

Some also reported absences throughout the physical activity program due to lack of energy, chronic pain, and infections. Though physical activity reduces risk factors against cardiovascular and metabolic diseases (Lavis et al., 2007; Naci & Ioannidis, 2013; Thompson et al., 2003), the extensive effect a SCI has over all physiological systems of the body predisposes them to unforeseen health complications (World Health Organization, 2013). Lack of access to information on physical activity opportunities directed to individuals with SCI was the main cause of inactivity for a few of participants before learning about SCIPA Com. This highlights the importance of conveying information to patients and community dwelling individuals with SCI through various communication outlets.

Demographic differences between the active and inactive groups were observed in two other physical categories: gender and years following SCI. According to Rauch et al. (2013), women with SCI are at a higher risk of inactivity associated to gender role activities (such as household tasks), lack of social support, and being less competitive and interested in sports compared to men. Sustaining a SCI for longer periods also seems to affect physical activity adherence, as observed by Kehn and Kroll (2009). The independent factors that lead to inactivity among the aging population (including people with SCI) is unclear, though they may be associated with age-related impairments (Fullerton et al., 2003).

Psychological issues

Psychological changes in both groups were influenced by their improved knowledge in physical activity and social involvement. In fact, health literacy is a key aspect for stronger community ownership and positive health outcomes (Raeburn et al., 2006). Once communities were able to identify problems and implement effective action plans, significant public health advances were achieved. Community-based organisations in Canada also revealed high adherence rates (88%) of participating regions (Gainforth et al., 2014). Along with increased social

participation and self-confidence, participants were motivated by physical improvements and through goal setting, as observed in Wise et al.'s program (Wise et al., 2009).

Financial issues

The financial situation of a household has shown to significantly influence physical activity participation among individuals with SCI (Cowan, Nash, & Anderson-Erisman, 2012). A web-survey detected that SCI populations living in households with higher earnings were more active than an average cohort by 17% (Cowan et al., 2012; Martin Ginis et al., 2010e). SCIPA Com provided participants with funding to access fitness centres and professional guidance attempting to close the gap between hospitals and community fitness centres. Future analysis of the cost utility of a community physical activity program in Australia and New Zealand is warranted. A community program among sedentary adults in the USA conducted a community centre-based lifestyle intervention promoted behavioural skills training and structured physical activity programs at an accessible cost of \$46.53 USD and \$190.24 USD per participant per month (Sevick et al., 2000). Considering that all participants in SCIPA Com required personal training, these costs were higher and ranged from \$25 AUD per month (in cases where exercise professionals agreed to waive personal training fees) up to \$390 AUD per month at a discounted rate (\$150 for gym access and \$30 AUD per personal training session, twice a week). Disability pensions in Australia are currently \$766 AUD per fortnight (Department of Human Services of the Australian Government, 2014), which restrains many participants from hiring exercise professionals on an individual basis.

Gym-access fees could be negotiated directly with managers of community fitness centres or entirely covered by selected public institutions. YMCA community fitness centres currently offer memberships starting at \$25 AUD per month and additional services are negotiable according to one's needs. Examples of public institutions that could fully fund these services are the *Transport Accident Commission* (TAC, in cases of motor-vehicle accidents induced SCI) and the *National Disability Insurance Scheme* (National Disability Insurance Scheme, 2014), also known as *DisabilityCare Australia*. These governmental initiatives need to be actioned to offer affordable physical activity opportunities and guarantee the longevity of such practices (Bauman et al., 2012; Kohl et al., 2012; Raeburn et al., 2006). In return, physically active populations with SCI could improve their health

status and prevent secondary health comorbidities while reducing the onus on public and private health care systems (Vuori et al., 2013)

Researchers have established the idea of physical activity as a form of treatment with comparable effectiveness to other preventive, therapeutic, and rehabilitative modalities (Naci & Ioannidis, 2013). Statements of similar nature have raised questions among scientists involved in public health promotion initiatives and equity issues. Vuori et al. (2013) proposed that physical activity should be treated at the same level as pharmaceuticals and medical interventions. Like medical services, they propose that consumers need to be reimbursed for the provision of prescriptions and delivery of physical activity programs. It would seem that one way to achieve this would be through policy changes and strong advocacy in the community and medical level.

3.9 CONCLUSIONS

This study was the first to trial translational research for people with SCI in community fitness centres, moving towards an ecological model and away from experiments based in institutionalised organisations (i.e. hospitals or research centres). The intervention was further provided by service personnel in the community (i.e. exercise professionals), which has greater transferability to the community compared to studies purely conducted by rehabilitation professions or universities. Regarding barriers and facilitators for physical activity in the Australian and New Zealander cohorts analysed, outcomes validated findings reported by North American and Dutch SCI populations (Kehn & Kroll, 2009; Rimmer et al., 2004; Vissers et al., 2008).

Compared to inactive individuals with SCI, active people have more awareness and access to information and resources on physical activity and associated benefits. Additionally, they demonstrate higher interest and motivation in sports and exercises. After SCIPA Com, active individuals reiterated their perceptions towards barriers, such as financial constraints, secondary health problems, and social barriers (i.e. family and work commitments). Only one barrier was more prevalent in the post-assessment: accessibility in community fitness centres, e.g., gym equipment placed in an upper level of the fitness centre with no

lift access; lack of accessible bathrooms; lack of transportation or reliance on third parties to arrive at training locations, and unsuitable terrains for wheelchair access.

On the other hand, individuals with SCI from the inactive group effectively participated in physical activity and perceived less barriers regarding costs, motivation, physical and psychological limitations in the post-intervention phase. Interestingly, the focus of the second assessment was redirected to other issues, such as secondary health problems and lack of transportation. Several participants attributed great importance to the lack of access to information on physical activity regarding options, proper technique, and availability that led them to being inactive in the first place (before SCIPA Com). Several measures were identified to provide more structure for physical activity practice. A summary of these action plans are displayed on **Tables 3.5** and **3.6**, respectively.

3.10 LIMITATIONS

Results cannot be generalised due to the non-randomised purposive sampling selection process used to recruit participants in Australia and New Zealand. In the qualitative component, the use of purposive sampling was necessary to include representatives from all subcategories (according to characteristics of their injury) thus including a wide range of forms of SCI. Participants were also informed of the possibility of joining a structured physical activity program following initial assessments, which may have generated a pre-selection bias. Mainly those interested in joining SCIPA Com would have provided data for this study.

Most participants were males, Caucasian, well-educated and from affluent regions in Australia and New Zealand. These countries' public health care systems (Medicare and ACC) generally offer comprehensive assistance to SCI patients in the initial and follow-up phases of rehabilitation (Wilson et al., 2013). Patients based in metropolitan areas also have better access to services due to specialised services being only available in larger centres. As such, results may not be applicable to all people with SCI, specific sub-groups or those with lower average income. Furthermore, barriers and facilitators for physical activity need to be tested through level I and II evidence research to support cross-sectional and qualitative information. The main barriers and facilitators for physical activity are yet to be tested on SCI populations from multiple centres utilising assessment tools with higher sensitivity.

Table 3.5. Comparison between active and inactive individuals with SCI regarding perceived barriers and facilitators to physical activity following SCIPA Com.

<i>Active</i>	<i>Inactive</i>
<p>Barriers</p> <p>Non accessible community fitness centres. Financial constraints. Secondary health problems associated to physical and psychological functioning. Social commitments with family, work, and lack of time to engage in physical activity. Extreme weather conditions. Lack of motivation and energy to exercise. Lack of assistance while exercising. Lack of information on other types of physical activity or opportunities. Incontinence issues</p> <p>Facilitators</p> <p>Assistance from exercise professionals with knowledge in SCI. Improved mental well-being. Accessible facilities and equipment to engage in physical activity. Financial assistance to afford memberships in community fitness centres and equipment. Greater interest and motivation in physical activity. Structured physical activity programs. Increased awareness and access to information and resources on physical activity and associated benefits. Socialisation during training and support from family and friends to exercise. Programmed bowel and bladder management prior to and during training. Good weather conditions. Community health initiatives aimed at individuals with SCI. Knowledge on how to exercise.</p>	<p>Barriers</p> <p>Non accessible community fitness centres. Secondary health problems. Lack of transportation. Lack of access to information on physical activity opportunities. Lack of physical ability to perform exercises independently. Lack of motivation and/or psychological issues (i.e. depression, anxiety).</p> <p>Facilitators</p> <p>Accessible community fitness centres and efficient transportation. Financial assistance to afford memberships in community fitness centres and personal training. Motivation to participate in a physical activity program. Advertising on physical activity opportunities and sports tryout events. Community health initiatives aimed at individuals with SCI or other forms of physical disabilities. Structured physical activity programs. Assistance from exercise professionals with knowledge in SCI. Information on the benefits of physical activity and on how to exercise. Socialisation in the gym environment. Increased physical ability and fitness. Programmed bowel and bladder management prior to and during training.</p>

Table 3.6. Action plans to increase physical activity levels among those living with SCI in community-based fitness centres.

Action Plans	
1.	Establishment of a referral system between hospitals and community fitness centres;
2.	Increased advertising of physical activity opportunities through suitable communication channels (e.g. via social media);
3.	Fitness centres' compliance with accessible architectural policies and provision of accessible gym equipment;
4.	Education and support for assistants and exercise professionals on adapted physical activity and motivational strategies;
5.	Community outreach to identify people with SCI;
6.	Financial support for gym memberships and acquisition of accessible equipment
7.	Goal setting and periodic re-assessments according to the clients' objectives;
8.	A personalised physical activity program to meet the individual needs of a person with SCI; and lastly
9.	More substantial changes in terms of policy and infrastructure to ensure availability of programs for populations at a higher risk of inactivity throughout an extended period of time.

Chapter 4: Spinal Cord Injury and Physical Activity in the Community (SCIPA Com)

STUDY 2

Chapter 4 outlines *Study 2*, a quasi-experimental study that comprised two stages:

Stage 1: Risk management and transference of knowledge to exercise professionals via *T3-SCI®*; and

Stage 2: Implementation of a community-based physical activity programs for people with SCI.

Study 2 is detailed in the following sections:

Section 4.1 Introduction on the benefits of physical activity and the development of SCIPA Com.

Section 4.2 Methodology and research design used to implement SCIPA Com.

Section 4.3 Operational definition of the cohorts analysed: active and inactive individuals with SCI, as well as exercise professionals.

Section 4.4 Procedures used for the execution of SCIPA Com, timeline of data collection, as well as the measures and instruments utilised (*T3-SCI®*, PARA-SCI, PSFS, WHOQOL-BREF, and RSS).

Section 4.5 Test protocol used to assess participants within SCIPA Com.

Section 4.6 Statistical analysis performed.

Section 4.7 Results collected within SCIPA Com.

Section 4.8 Discussion of the quantitative findings on time engaged in LTPA, functional goal attainment, self-esteem, and quality of life over four time periods.

Section 4.9 Conclusions drawn from *Study 2*. And

Section 4.10 Ethics and limitations of this study.

4.1 INTRODUCTION

Accumulating evidence within the literature has established that structured LTPA for individuals with SCI is associated with better health and fitness (Gainforth et al., 2014; Hicks et al., 2011; Martin Ginis et al., 2011a; Martin Ginis et al., 2012i; Valent et al., 2007). Thus, physical activity has been reinforced to prevent secondary problems, enhance functional abilities, stimulate psychological benefits, and increase community integration. Potential cost savings of early prevention/intervention also derive from reduced expenses of hospitalisations, powered mobility aids, and additional personal care (Ackery et al., 2004; Bowne, Russell, Morgan, Optenberg, & Clarke, 1984; Ipsen, Ravesloot, Seekins, & Seninger, 2006; Paul et al., 2013). However, SCIs predominantly lead to sedentary behaviour which can be attributed in part to barriers present in the community and lack of motivation (Kehn & Kroll, 2009; Martin Ginis et al., 2010e). Whatever the barriers, the fact remains that inactivity levels in the SCI population are among the highest compared to any other cohort (Hallal et al., 2012; Kroll et al., 2007g).

Interventions against sedentarism among people with SCI have been the focus of several recent studies (Froehlich-Grobe et al., 2014; Hicks et al., 2003; Pelletier, 2014; Wise et al., 2009) given its importance in improving health and reducing economic burden on the individual, their families, and national public healthcare systems (Cao et al., 2011; Collie et al., 2010). Various researchers have identified measures that increase physical activity participation, reduce the costs of physical activity participation and time travelled by promoting programs at home or in the community (Block et al., 2010; Froehlich-Grobe et al., 2014; Martin Ginis et al., 2012a; Pelletier, 2014; Wise et al., 2009). These training programs incorporated professional assistance, exercise equipment, education on exercises and benefits, safety precautions, self-regulation strategies, and counselling.

Several studies have shown that physical activity training improves general health and increased time engaged in LTPA, i.e. upper limb strength, endurance, range of motion, and general health (Block et al., 2010; Froehlich-Grobe et al., 2014; Pelletier, 2014; Wise et al., 2009). These improvements are attributed to increased fitness, energy expenditure, glucose metabolism, and balanced lipid profiles (Alwaili et al., 2010; Thompson et al., 2003). Such physiological adaptations to physical activity have also been related to the prevention of serious public health concerns, namely cardiovascular and metabolic conditions, such as coronary heart disease

and type II diabetes mellitus (Franklin et al., 2014; Lavis et al., 2007; Naci & Ioannidis, 2013; Thompson et al., 2003).

Physical activity has also been posited as the main predictor of psychological well-being, reflecting in higher quality of life measures (Anneken et al., 2010). In turn, quality of life was deemed by various authors one of the main (if not the most important) health outcome available to test the effectiveness of an intervention (Hill et al., 2010; Kawanishi & Greguol, 2013; Peter et al., 2014; Ravenek, Ravenek, Hitzig, & Wolfe, 2012). Improved quality of life further implicated positive affective emotions such as enjoyment and energy, self-esteem, self-efficacy (Anneken et al., 2010; Tawashy et al., 2009; van Leeuwen et al., 2012a; van Leeuwen et al., 2012f); and reduced cases of depression, stress and anxiety (Gioia et al., 2006; Hicks et al., 2003). In many situations, involvement in wheelchair sports and athletic associations led to identity reconstruction, shifting ones' bibliographic narrative into becoming highly active (Levins et al., 2004) or even competitive athletes (Machida, Irwin, & Feltz, 2013).

Within the group of psychological resources, investigations have produced important evidence pertaining the role of motivation and self-efficacy on the completion of tasks and overcoming barriers (Arbour-Nicitopoulos et al., 2009; Carbonneau, Vallerand, & Lafreniere, 2012; Kroll et al., 2007a; Peter et al., 2012). Barbin and Ninot (2008) also reported significant increases in global self-esteem following a one-week adapted skiing program. Improvements in global self-esteem is believed to positively influence life satisfaction and reduce feelings of loneliness (Tzonichaki & Kleftharas, 2002). Though self-esteem in the SCI population was highly correlated to recreational activity (Coyle et al., 1994), it has not been well evaluated in the physical activity context. Further examination on the effects of physical activity in the community setting on self-esteem levels is still required.

Active life-styles within the SCI population have been also facilitated via successful rehabilitation experiences in the care and management of their condition (Kehn & Kroll, 2009; Levins et al., 2004; Vissers et al., 2008); efficient referral systems from rehabilitation services to the community setting (Pelletier et al., 2014; Rimmer & Henley, 2013); increased community involvement (Gainforth et al., 2014; Raeburn et al., 2006); and self-regulatory and self-efficacy skills towards physical activity (Brawley et al., 2013; Latimer-Cheung et al., 2013). The social aspect of LTPA and sports participation in the community has displayed improved life satisfaction, reduced negative emotions and thoughts, and increased motivation to sustain physically active life-styles (Levins et al., 2004; Müller et al., 2012).

Principals established for the general population may also be effective for the SCI population. An extensive review on interventions to increase physical activity in the general population strongly recommends community-wide health education initiatives, social support, multi-site and multi-component interventions to modify physical activity behaviours (Kahn et al., 2002). Conversely, only a few studies have involved the wider community as integral parts of their intervention or have effectively engaged the target SCI population (Elley et al., 2007; Gainforth et al., 2014). Studies have identified the importance of customised physical activity programs (Schwarzer, Lippke, & Luszczynska, 2011) in considering each individual's goals, personality trait and attributes as well as their physical strengths (Buntinx, 2013; Park & Peterson, 2009).

In order to ensure physical activity participation for individuals with SCI, first of all, barriers regarding accessibility, affordability, and knowledgeable professional assistance need to be addressed (Kehn & Kroll, 2009; Rimmer & Marques, 2012; Robertson et al., 2011; Vissers et al., 2008). Cost-efficiency and access of support systems may well be attained by substituting researchers/interventionists with highly trained community health educators (Sevick et al., 2000). Exercise professionals present a resourceful background in physical activity/exercise knowledge and practice, with the advantage of being readily accessible in community fitness centres (Moore et al., 2011). They are trained to adopt individualised approaches, motivate and educate clients on health and safety (Malek et al., 2002; National Strength and Conditioning Association, 2011). Collaborations between researchers and exercise professionals may encourage the exchange of expertise and development of physical activity programs suited to clients.

Rimmer and Henley (2013) proposed a transitional *therapist-to-trainer* model to expedite the reintegration of individuals with SCI in a community-based fitness facility devoted for people with disabilities. In hindsight, the scarce availability of such amenities limits the dissemination of this ideal. As an alternative, we proposed that associations between rehabilitation professionals and community fitness centres would foster support and knowledge between clients with SCI and exercise professionals. SCIPA Com is an original initiative developed to fulfil this demand. Researchers from Curtin University, The University of Western Australia and The University of Melbourne designed SCIPA Com to transition from a model of institutionalised health care of individuals with SCI to a sustainable model of health promotion and community integration. The program offered fitness centres theoretical and financial support to address accessibility issues and detrimental

levels of sedentarism among individuals with SCI. The main objective of this study was to increase LTPA in the community for the SCI population, leading to improved functional ability, self-esteem and quality of life.

4.1.1 Research questions

The following research questions guided *Study 2*:

- Do structured physical activity programs in the community increase physical activity levels of people with SCI?
- Do physical activity levels correlate to functional goal achievement, self-esteem, and quality of life?
- Are there differences between the outcomes of highly active individuals compared to inactive people with SCI?
- Do individuals with SCI adhere to long-term physical activity after participating in a structured program in the community?

4.1.2 Objectives

The objectives of *Study 2* were:

- Promote re-integration of people with SCI into physically active life styles post-discharge from rehabilitation services through an eight-to-twelve week customised physical activity program based on the clients goals, physical and personality strengths (i.e. SCIPA Com);
- Evaluate whether access to qualified exercise professionals, accessible fitness centres, and initial financial support provided by SCIPA Com improves LTPA levels performed by people with SCI across different periods (baseline, immediately after SCIPA Com, six and nine months after the beginning of SCIPA Com);
- Document the correlation between LTPA levels and functional goal achievement, self-esteem, and quality of life among individuals with SCI.

4.1.3 General hypothesis

The hypothesis drawn from literature was:

- That a model of health promotion and community integration for individuals with SCI in community fitness centres can lead to an increase in LTPA levels, functional goal achievement, quality of life, and self-esteem among this cohort.

Specific hypothesis

- That functional goal achievement, quality of life, and self-esteem will increase with improvements in LTPA levels.
- That changes in LTPA levels, function, quality of life and self-esteem will be higher in the previously inactive SCI population.
- That changes to baseline LTPA levels will be significant after experiencing a supervised eight-to-twelve week physical activity program and maintained in the follow-up assessment periods.

4.2 METHODOLOGY AND RESEARCH DESIGN

SCIPA Com is a quasi-experimental research developed in two stages: 1) training of exercise professionals on risk management and adapted physical activity for people with SCI; and 2) implementation of customised physical activity programs for clients with SCI, based on their goals, physical and personality attributes, for the duration of eight-to-twelve weeks. Baseline measures were utilised as the parameter for comparisons in follow-up periods. A stepped-wedge design of control individuals who would have their physical activity programs delayed for the initial three months was initially attempted; however, this delay was counterintuitive with our objectives and participants were demotivated when subjected to long waiting periods. Hence, a control group was not employed in this study.

Recruitment was initiated in the state of Western Australia in the year 2011, followed by the inclusion of participants from Victoria in 2012, extending the services to Queensland and Christchurch in 2013. Two main cohorts were targeted for this study: clients with SCI and exercise professionals. The later were employed by the participating community fitness centres and not associated with clinical or higher

education institutions. The nature of the study was entirely voluntary and all participants were entitled to withdraw from the study at any time without disadvantages. Entry into the program was subjected to the time required by the exercise professional to complete their training and availability of their respective client(s) with SCI.

Curtin University Human Research Ethics Committee approved all procedures (HR80/2010) and participants were informed of the study's implications before providing written consent (**Appendix 5**. Information Sheet for Participants with SCI). The SCIPA Com model was based on the delivery of an accredited educational program, *Train the Trainers Spinal Cord Injury program (T3-SCI®)* (**Appendix 6**), aimed at exercise professionals. The main focus of the course was to improve safety and accessibility of community fitness centres for people with SCI. Based on a previous study (i.e. *Study 1*) on barriers and facilitators for physical activity conducted by SCIPA Com researchers, the core accessibility issues were identified and addressed to attend the SCI population in community fitness centres. Participants with SCI were assessed on changes in LTPA levels, functional goal achievement, self-esteem, and quality of life scores in four different time periods: before SCIPA Com, immediately after SCIPA Com (3 months after baseline), six and 9 months following intervention.

4.3 PARTICIPANTS

Two main cohorts were involved in the SCIPA Com program: clients with SCI and exercise professionals.

4.3.1 Clients with SCI

Participants from *Study 1* on barriers and facilitators to physical activity were invited to take part in the SCIPA Com program and recruitment was amplified using similar methods as the prior study: online advertisements circulated by SCI organisations and networks, referrals from physiotherapists and social workers, and through snowball sampling method (Arcury & Quandt, 1999). Individuals with SCI were included if presenting the following criteria:

- aged between 18 and 80 years;
- diagnosed with a complete or incomplete SCI for one year or more;
- presenting intact cognitive function;
- living independently in the community;
- screened and medically approved to engage in physical activity prior to commencement;
- capable of executing active exercises;
- and SCI classified as traumatic and non-traumatic were included as the clinical signs, symptoms, and general therapeutic principles apply equally (McDonald & Sadowsky, 2002).

Subjects were excluded from this study under the following criteria:

- presenting full recovery of movement and function post-injury;
- residing in hospitals or care and rehabilitation facilities;
- unable to perform active physical activity in fitness centres due to either medical contraindications or a SCI classified as AIS A (complete) C4 or above according to the *International Standards for Classification of Spinal Cord Injury*, written by the Neurological Standards Committee of the American Spinal Injury Association (ASIA) (Kirshblum et al., 2011).

4.3.2 Exercise professionals

The exercise professionals involved were required to meet the following criteria:

- accreditation in fitness training with their country's professional representation boards (*Fitness Australia* and *Register of Exercise Professionals* in New Zealand);
- certificates levels 3 or 4 in fitness training or a university degree in the health sciences;
- a minimum of one year of experience working in the fitness industry;
- employed by community fitness centres;
- recipient of managerial approval to operate SCIPA Com in their work establishments.

4.4 PROCEDURES

The following procedures constitute the SCIPA Com program (for more details, see **Appendix 7. SCIPA Com: A Model of Health Promotion and Community Integration**). Measures adopted to reduce the barriers and facilitate a safe and supportive experience in the fitness centre context included two stages: 1) training of exercise professionals through *T3-SCI®*; and 2) implementation of SCIPA Com

4.4.1 SCIPA Com: Stage 1

SCI organisations (e.g. Australian Quadriplegic Association, Escare, Independence Australia, Paraplegic Benefit Fund Australia, Spinal Cord Injury Network, Spinal Hub, and Wheelchair Sports Association WA) were initially contacted to determine the feasibility of the SCIPA Com program in both metropolitan and rural areas. Managers of accessible community fitness centres were then approached to recruit exercise professionals interested in undertaking the *T3-SCI®* course within a one month interval. Exercise professionals were informed of the program and consented to participate. *T3-SCI®* was used to educate exercise professionals on the principals of risk-management in training people with SCI. They were required to read the content, test their knowledge through multiple-choice questions at the end of five units, submit assignments on risk-management and accessibility, and develop physical activity programs for clients with SCI based on their personality, strengths and goals.

Train the Trainers Spinal Cord Injury® course (T3-SCI®)

This educational course for exercise professionals aimed on theoretical and practical aspects of working with the population with SCI. Experienced physiotherapists and academics from Curtin University developed the material included in this teaching program. External assessors from the University of Western Australia (S.A.D) and the University of Melbourne (M.P.G.) reviewed and approved information quality. *T3-SCI®* is accredited by the national health and fitness industry associations of Australia (*Fitness Australia*) and New Zealand (*Registry of Exercise Professionals - REPs*). The completion of this course awarded exercise professionals 15 continuous education credits in Australia and 20 in New Zealand to meet re-registration requirements with their representing bodies. No charges incurred with participation in this program.

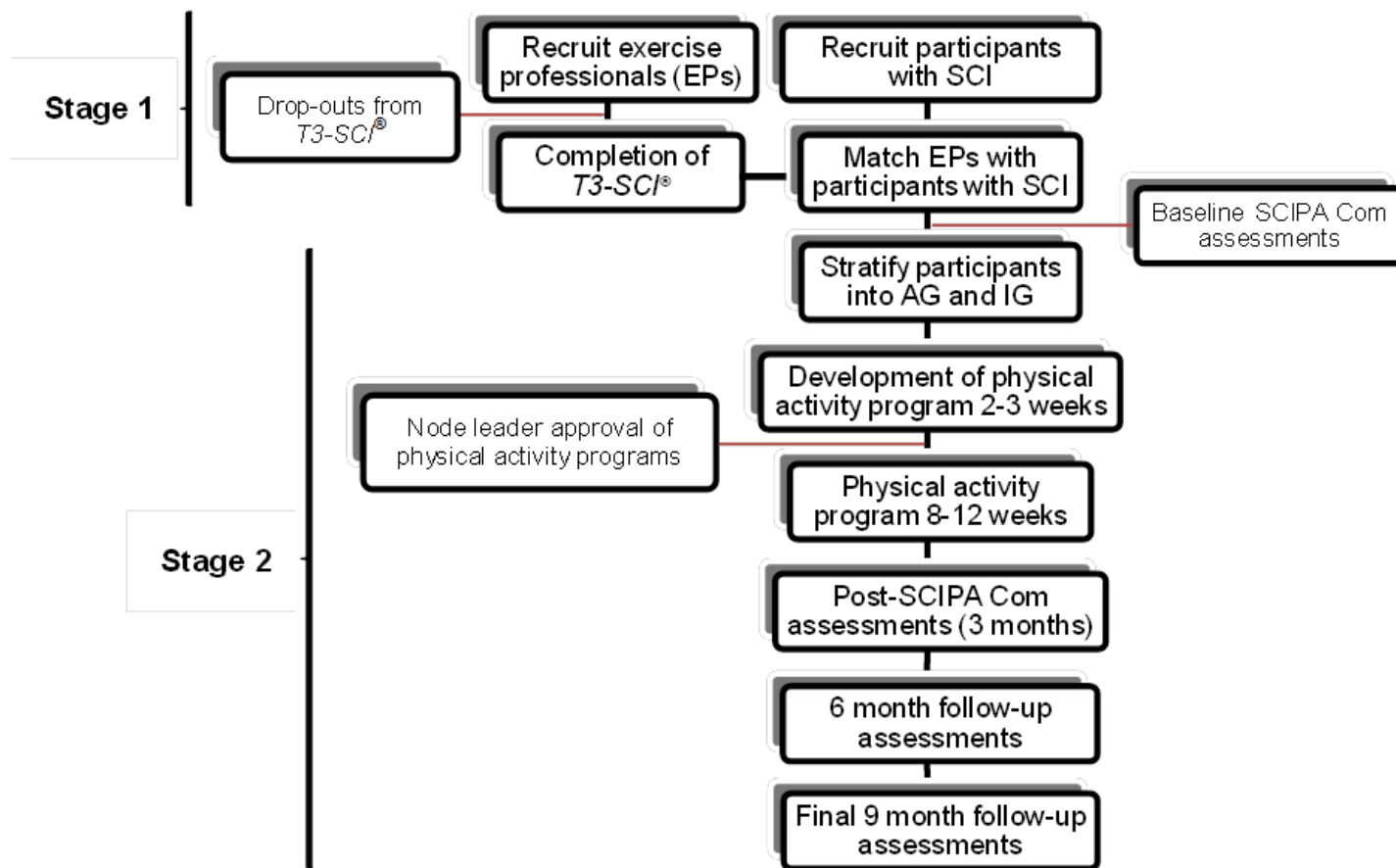


Figure 4.1. Study 2: SCIPA Com design illustrating the chronological order of recruitments, assessments and interventions. Telephone follow-ups were held to monitor changes in physical activity participation, functional goal achievement, self-esteem and quality of life post-intervention. Note: *Train the Trainers Spinal Cord Injury*® (T3-SCI®), Exercise Professionals (EPs), Active Group (AG), and Inactive Group (IG).

The *T3-SCI*® content is divided into nine units covering fundamental information on SCI (**Appendix 6**). The course was delivered in two formats: online to enable inclusion of remote communities (Esperance and Dunsborough in Western Australia; Cairns in Queensland; and Ballarat in Victoria), and as half-day courses typically for large centres (Perth and Melbourne in Australia, and Christchurch in New Zealand). The online course required approximately 10 hours of studying through flexible delivery content. Half-day courses were delivered five hours of theory in-class and five hours of assignments to develop at home. Exercise professionals were required to finish the course and assignments within a month.

Following the completion of the course, exercise professionals were assigned to physiotherapists (called the *Node Leaders*) for supervision on their progress and assignments. The training course included the provision of templates and professional drawings of people with SCI utilising gym equipment to guide the development of physical activity programs and assignment. Authors of *T3-SCI*® also provided a facility access checklist for fitness centres (**Appendix 6.1**), pre-training risk management action plan (**Appendix 6.2**), examples of physical activity programs for individuals with SCI in fitness centres (**Appendix 6.3**), and the *T3-SCI*® *Safety Procedures* booklet (**Appendix 6.4**) in the event of an emergency. This booklet covers first-aid measures in cases of autonomic dysreflexia, heat exhaustion, orthostatic hypotension, loss of consciousness, skin damage, fractures, and falls from wheelchair. Exercise professionals were advised to keep this booklet at an easy to access location in the fitness centre.

Once community fitness centres were prepared to receive clients, SCI networks invited the SCI community to partake in an eight-to-twelve week physical activity program in their nearest participating facility. Clients with SCI initially contacted researchers from SCIPA Com to express interest in joining the program. The PhD candidate met the SCI client to determine their location and preferences for nearby fitness training centres. Once the preferred location was identified, the PhD candidate and supporting SCIPA Com staff negotiated terms with managers and exercise professionals of the chosen community fitness centre.

Exercise professionals working in community fitness centres were matched with clients with SCI by geographical proximity to the client's home address. At the initial contact with clients with SCI exercise professionals discussed the functional goals and ambitions of their clients. Subsequently, and as part of the SCIPA com educational program, the exercise professionals were required to submit an assignment that outlined the planned physical activity program based on the

characteristics of their specific client. Personality and physical attributes, as well as specific goals of each client with SCI were considered in the process. These programs were reviewed and approved by *Node Leaders* before starting the program. Exercise professionals were advised to contact their *Node Leaders* via telephone or emails for guidance. On occasions, node leaders provided on-site assistance. Altogether, these measures aimed to provide ongoing support for risk management and enable safe access to fitness centres by individuals with SCI.

4.4.2 SCIPA Com: Stage 2

Before commencing the SCIPA Com program, participants with SCI provided self-reported demographic (i.e. gender, age, SCI cause, SCI classification, years since SCI, use of assistive technology) and anthropometric (i.e. weight) measures. Subsequently, baseline assessments of four different outcomes were conducted: LTPA levels, functional goal achievement, self-esteem, and quality of life.

Physical Activity Levels

The *Physical Activity Recall Assessment for Individuals with SCI (PARA-SCI)* (Latimer et al., 2006j) was used to measure physical activity levels among individuals with SCI. Participants were asked to provide an estimate of total time in minutes spent performing self-reported mild, moderate and heavy intensity (refer to **Figure 4.2**) LTPA as well as lifestyle activity (i.e. ADL, e.g. personal hygiene, chores, work, and passive leisure activity) for the three previous days leading to the assessment date. The assessor was responsible for completing the PARA-SCI tool and PARA-SCI Time Table (**Appendix 8**).

Functional Goal Achievement

Functional goal achievement was evaluated through the *Patient-Specific Functional Scale (PSFS)* (Stratford et al., 1995). Participants nominated three or more activities with which they have difficulties due to their condition. Subjects scored these activities on an 10-point numeric rating scale (NRS) where 1 represents “unable to perform activity” and 10 represents “able to perform activity at the level aimed at the start” (See **Figure 4.3**). Higher scores indicated lower levels of disability, warranted that activities chosen were realistic and achievable. Clinical significance was detected with differences in scores equal to or greater than 1.2 (Hefford et al., 2012).

Para-SCI Intensity Classification System

	Nothing at all	Mild	Moderate	Heavy
<i>How hard are you working?</i>	Includes activities that even when you are doing them, you do not feel like you are working at all	Includes physical activities that require you to do very light work. You should feel like you are working a little bit but overall you should not find yourself working too hard	Includes physical activities that require some physical effort. You should feel like you are working somewhat hard but can maintain the effort for a long time	Includes physical activities that require a lot of physical effort. You should feel like you are working really hard (almost at your maximum) and can only do the activity for a short time before getting tired. These activities can be exhausting
<i>How does your body feel?</i>				
Breathing and heart rate	Normal	Stays normal or is only a little bit harder and/or faster than normal	Noticeable harder and faster than normal but not extremely hard or fast	Fairly hard and much faster than normal
Muscles	Normal	Feel loose, warmed up and relaxed. Feel normal temperature or a little bit warmer and not tired at all	Feel pumped and worked. Feel warmer than normal and starting to get tired after a while	Burn and feel tight and tense. Feel a lot warmer than normal and feel tired
Skin	Normal	Normal temperature is only a little bit warmer and not sweaty	A little bit warmer than normal and might be a little sweaty	Much warmer than normal and might be sweaty
Mind	Normal	You might feel very alert. Has no effect on concentration	Requires some concentration to complete	Requires a lot of concentration

Figure 4.2. PARA-SCI Intensity Classification System for the rating of physical exertion required for every activity performed. Reprinted from *Physical Activity Recall Assessment for People with Spinal Cord Injury: Administration and Scoring Manual* (p. 12), by K. A. Martin Ginis and A. Latimer, 2008, Hamilton: Ontario: McMaster University. Copyright 2008 by McMaster University. Reprinted with permission.

The Patient-Specific Functional Scale

This useful questionnaire can be used to quantify activity limitation and measure functional outcome for patients with any neurological condition.

Initial Assessment

I am going to ask you to identify up to three important activities that you think you are capable of achieving that you currently are not able to do or perform at the expected level of performance. Evidently, we are talking about outcomes that are achievable in the future say 3 – 6 months.

Follow-up Assessments

When I assessed you on (state previous assessment date), you told me that you had difficulty with (read all activities from list at a time). Today, do you still have difficulty with: (read and have patient score each item in the list)?

Patient-specific activity scoring scheme (Point to one number)

	1	2	3	4	5	6	7	8	9	10
Unable to perform activity										Able to perform activity at the level I wanted to achieve at the start

(Date and Score)

Activity	Initial					
1.						
2.						
3.						
4.						
5.						
Additional						

Total score = sum of the activity scores/number of activities

Minimum detectable change (90%CI) for average score = 1.2 points

Figure 4.3. The Patient Specific Functional Scale (PSFS). Reprinted from "Assessing disability and change on individual patients: A report of a patient specific measure", by P. Stratford, 1955, *Physiotherapy Canada*, 47, p. 258-263. Copyright 1995 by the University of Toronto Press.

Self-Esteem

Self-esteem measures were obtained through the *Rosenberg Self-Esteem Scale (RSS)* (Robins et al., 2001; Rosenberg, 1979). The SCI cohort rated ten statements on a four-point scale from strongly agree (rated 3) to strongly disagree (rated 0) (Rosenberg, 1999) (See **Figure 4.4**). The scores ranged from 0 to 30, in which 15 to 25 were considered normal and below 15 suggested low self-esteem.

Rosenberg Self-Esteem Scale

The scale is a ten item Likert scale with items answered on a four point scale - from strongly agree to strongly disagree.

Instructions

Below is a list of statements dealing with your general feelings about yourself. If you strongly agree, mark the box "Strongly Agree". If you agree with the statement, mark the box "Agree". If you disagree, mark the box "Disagree". If you strongly disagree, mark the box "Strongly Disagree".

STATEMENT	Strongly Agree	Agree	Disagree	Strongly Disagree
I feel that I am a person of worth, at least on an equal plane with others.				
I feel that I have a number of good qualities.				
All in all, I am inclined to feel that I am a failure.				
I am able to do things as well as most other people.				
I feel I do not have much to be proud of.				
I take a positive attitude toward myself.				
On the whole, I am satisfied with myself.				
I wish I could have more respect for myself.				
I certainly feel useless at times.				
At times I think I am no good at all.				

Figure 4.4. Rosenberg Self-Esteem Scale. 10-item scale that measures global self-worth through the assessment of both positive and negative feelings about the self. Reprinted from *Society and the Adolescent Self-Image*, by M. Rosenberg, 1965, Princeton, NJ: Princeton University Press. Copyright 1965 by the Morris Rosenberg Foundation.

Quality of Life

The *World Health Organization Quality of Life Scale - Bref (WHOQOL-BREF)* (Jang et al., 2004; World Health Organization, 1998) was used to measure quality of life (**Appendix 9**). Individuals with SCI rated on a five-point Likert-response scale the intensity, frequency, or personal assessment of 26 selected attributes of quality of life throughout the previous two weeks (World Health Organization, 1998). Out of the 26 items comprised in WHOQOL-BREF, 24 provided measures of 4 domains of quality of life: physical health (7 items), psychological health (6 items), social relationships (3 items), and environment (8 items), whereas the other 2 items measured overall quality of life and general health. Higher scores indicated better quality of life.

These standard clinical questionnaires have documented construct validity and intra and inter-rater reliability (see **Chapter 2: Literature Review**). The questionnaire items were presented verbally for participants; those that were not able to write and their responses had their answers manually recorded by the researchers of this study. Based on results obtained via PARA-SCI assessments, participants were stratified into the inactive group or active group according to their baseline physical activity levels. Those in the active group reported an average equal to or over 150 minutes of moderate-intensity LTPA or 60 minutes of vigorous-intensity LTPA per week; individuals that reported less time engaged in LTPA were stratified into the inactive group (American College of Sports Medicine et al., 2009; Buchner et al., 2008; Haskell et al., 2007). The stratification was pertinent due to LTPA recommendations set by the *American College of Sports Medicine and 2008 Physical Activity Guidelines for Americans*.

The main outcome measure analysed in this study was the average time clients with SCI engaged in moderate-to-heavy intensity physical activity. The focus was further directed to LTPA, as it is likely to be more sensitive to behavioural changes among sedentary individuals with SCI. In theory, people who are physically active may present less pronounced changes in outcomes overtime compared to their inactive counterparts, because they have integrated LTPA into their lifestyle already. The health promotion basis of this study was to target those who were not active. Changes in LTPA were recorded throughout time to determine the true translational effect of the proposed intervention.

4.5 TEST PROTOCOL

Prior to baseline assessments, two researchers in Australia (B.I.R.D.O) and New Zealand (C.S.) were trained to conduct evaluations utilising the PARA-SCI, PSFS, RSS, and the WHOQOL-BREF instruments. Each assessment was carried out in person or via telephone calls and required one-to-two hours to complete. Moderate-to-heavy intensity of LTPA, expressed in minutes per week, was assessed in four different time periods: baseline (prior to the intervention period), three months (immediately after the eight-to-twelve week physical activity program), six months and nine months after the commencement of SCIPA Com. On the same occasions, participants were measured for functional goal achievement, self-esteem, and quality of life to determine changes in secondary health outcome measures during the physical activity program. These phone calls were also performed to inform participants of their progress according to assessments and motivate them to continue physical activity training post-SCIPA Com.

4.6 STATISTICAL ANALYSIS

Descriptive statistics (means and standard deviations or median and interquartile range) of participants at baseline and the outcome measures at each of the four assessment periods were calculated using STATA/IC 13.1 for Windows (StataCorp LP, College Station TX, USA, 2013). Independent samples t-tests (for normally distributed data) and Mann-Whitney U tests (for nonparametric data) were used to compare differences in baseline continuous variables among the active and inactive groups; whereas the chi-square tests were used for categorical data.

Outcome data were initially inspected and corrected for potential data entry errors. The distribution of variables was screened through the analysis of normality statistics (skewness and kurtosis), histograms, and boxplots. Standard errors were bootstrapped using 1000 replications to account for slight deviations from normal distribution (Delgado & Manteiga, 2001).

Subsequently, LTPA levels, functional goal achievement, self-esteem, and quality of life scores were assessed using separate linear mixed models. Individuals were included as a random intercept to account for the repeated measurements.

Participants involved in at least two assessments (baseline and three month follow-up) were included in the statistical models (total used in analysis, N=64).

Linear contrasts between the estimated marginal means were used between follow-up periods three months, six months, and nine months after the beginning of the intervention against baseline values to determine interaction effects of baseline LTPA and time, estimated mean differences, 95% confidence intervals, and probability values. Interactions between LTPA levels and time were tested to determine differences between the two groups observed.

Alpha level adjustments for multiple comparisons were not undertaken as all hypotheses were established *a priori*. Where applicable and available, statistical significance was interpreted relative to thresholds of clinical significance ($P < .05$).

4.7 RESULTS

The following are the results for the baseline characteristics and outcome measures (LTPA levels, functional satisfaction, self-esteem, and quality of life) over four different assessment periods (baseline; three, six, and nine months).

4.7.1 Baseline characteristics of groups with SCI

From a total of 39 community health and fitness centres invited to participate in SCIPA Com, 32 (**Appendix 10**) engaged with SCIPA Com to offer 85 people with SCI (previously screened for *Study 1*), an opportunity to engage in supervised physical activity in their community. These centres were located in various cities in Australia (e.g. Perth, Dunsborough, and Esperance in Western Australia; Melbourne and Ballarat in Victoria; Cairns in Queensland) and New Zealand (Christchurch).

A total of 21 participants were excluded from analysis. Two participants from the inactive group and twelve from the active group did not engage in SCIPA Com. In the inactive group this was due to lack of interest (n=2). In the active group, the failure to engage in physical activity training were attributed to a lack of trained exercise professionals in their local fitness centres (i.e. lack of community involvement) (n=5), lack of interest (n=2), no response (n=2), health issues (n=1), personal issues (n=1) and one participant deceased before initiating the program (n=1) (refer to **Figure 3.1** in **Chapter 3**).

Six participants classified as inactive at baseline withdrew from the program before accomplishing a minimum of eight weeks of the SCIPA Com intervention as a result of chronic injuries (n=3) and loss of contact (n=3). One individual from the active group presented health issues before training was complete (n=1). Sixty-four participants successfully completed eight-to-twelve weeks of physical activity training and provided the three-month follow-up assessment (refer to **Figure 3.1** in **Chapter 3** to see the CONSORT flow diagram of participants in SCIPA Com). Data obtained from these 64 individuals were included in the statistical analysis. Their demographic and anthropometric characteristics are presented in **Table 4.1**.

Table 4.1. Baseline demographic characteristics of clients with SCI (N=64).

	Total (N=64)	Inactive (n=37)	Active (n=27)	P
Gender (%)				
Male	72	59	89	.01*
Female	28	41	11	
Age (y)	48.6 ± 13	48.9 ± 12.5	48.2 ± 14.6	.826
Body Weight (kg)	80.7 ± 19.7	82 ± 23.2	79 ± 14	.563
Cause (%)				
Traumatic	81	73	93	.047*
Non-Traumatic	19	27	7	
SCI Classification (%)				
Tetraplegia complete	17	21.5	11	.481
Tetraplegia incomplete	30	30	30	
Paraplegia complete	28	21.5	37	
Paraplegia incomplete	25	27	22	
Years since SCI (y)	9 (2-21)	9 (2-19)	10 (4-26)	.342
Assistive Technology (%)				
Manual Wheelchair	76	73	82	.113
Electric Wheelchair	11	19	0	
Crutches, Cane	8	5	11	
None	5	3	7	
LTPA levels (min)	19 (0-60)	0 (0-10)	60 (48-80)	.001#

Note. These figures reflect within-group frequencies and are not cumulative across rows. Values expressed as %, mean ± SD, or median and interquartile range (IQR).

* Significant differences between active and inactive sub-cohorts ($P < 0.05$) using independent t-test (continuous) and Chi square test (categorical).

Significant differences between active and inactive sub-cohorts ($P < 0.05$) using Mann-Whitney U.

Three demographic characteristics were statistically different at baseline between the active and inactive groups: gender, cause of SCI, and (as expected) LTPA levels. The odds ratio (OR) of being a male in the active group was 5.62 times more likely compared to being a female, with a 95% confidence interval (CI) ranging from 2.56 to 13.03 ($P < .001$). The active group presented an OR equal to 4.91 (95%CI: 1.93 to 14.03, $P < .001$) for having a traumatic SCI, i.e., they are almost five times more likely of having a traumatic SCI as the cause of their SCI compared to an inactive person.

Sixty-four clients with SCI completed full baseline and three months follow-up assessments and were included for preliminary analysis. The response rate reduced to 95.3% (61 participants) at six months follow-up assessments. The final follow-up period (nine months) was censored due to time constraints of the thesis enrolment, and only the first 40 subjects were contacted to complete all four assessments. All 40 individuals contacted provided full evaluations, maintaining a response rate of 100% (see response rates in **Figure 4.5**).

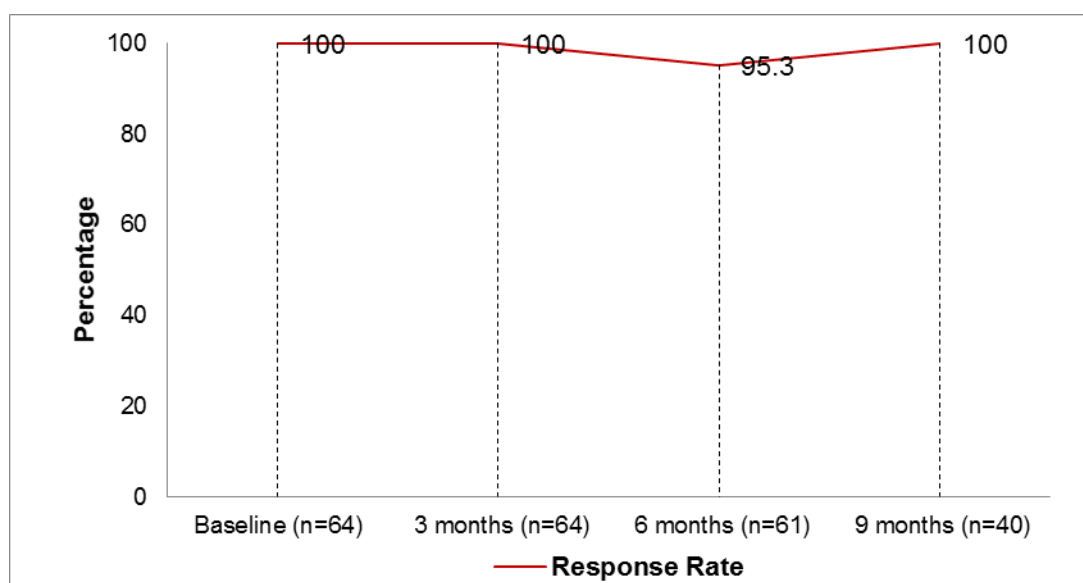


Figure 4.5. Response rates to full assessments provided by clients with SCI over four different time periods. The last follow-up assessment (9 months) presented a smaller sample size due to censure to the data collection time, and not due to dropouts.

A total of 95 exercise professionals enrolled in the program and obtained access to *T3-SCI*® online course. A high drop-out rate was observed mainly due to lack of response, and many were not able to complete the associated workload of a minimum of ten hours for the implementation of SCIPA Com. Incompletion rates could also be explained due to the fact that all exercise professionals needed to

register prior to looking at the course and level of information. Fifty exercise professionals completed the *T3-SCI*® course and were eligible to work with people with SCI. Clients were able to choose their preferred fitness training locations and therefore exercise professionals. As a result of the geographical matching, only 32 of the 50 trainers were sought by one or more of clients with SCI. Together, they performed a minimum of eight weeks and up to twelve weeks of supervised physical activity training.

A minimum of two sessions per week were conducted with duration of at least 30 minutes and a maximum of 90 minutes of physical activity per day. A variety of activities included endurance, strength, balance, proprioceptive training and muscle lengthening exercises according to the client's objectives, characteristics, and needs.

LTPA levels, functional goal achievement, self-esteem, and quality of life scores were more prominent at the three months assessment mark (immediately after SCIPA Com) and showed improvements in follow-up assessments (months six and nine) compared to baseline values. More details are included in the following sections.

4.7.2 Physical activity outcomes

The proportions of active and inactive individuals over each time period are illustrated on **Figure 4.6**. At baseline, 42.2% of participants were classified as active. The larger proportion of participants was considered inactive. Immediately after the three-month intervention period, the proportion of people exercising less than 30 minutes per day (inactive) decreased from 57.8% (n = 37) to 14% (n = 9). The rate of individuals that maintained adequate LTPA levels in the post-intervention follow-up periods was 66% (n = 40) at six months and 70% (n = 27) at nine months. Sub-group analysis revealed that the percentage of individuals in the active group that maintained LTPA levels above the threshold was 100% (n = 27) at three months, 89% at six months and 93% at nine months. A reduced proportion of people in the inactive group displayed LTPA above the threshold at three months (76%, n = 28), six month (47%, n = 17), and nine months (50%, n = 19).

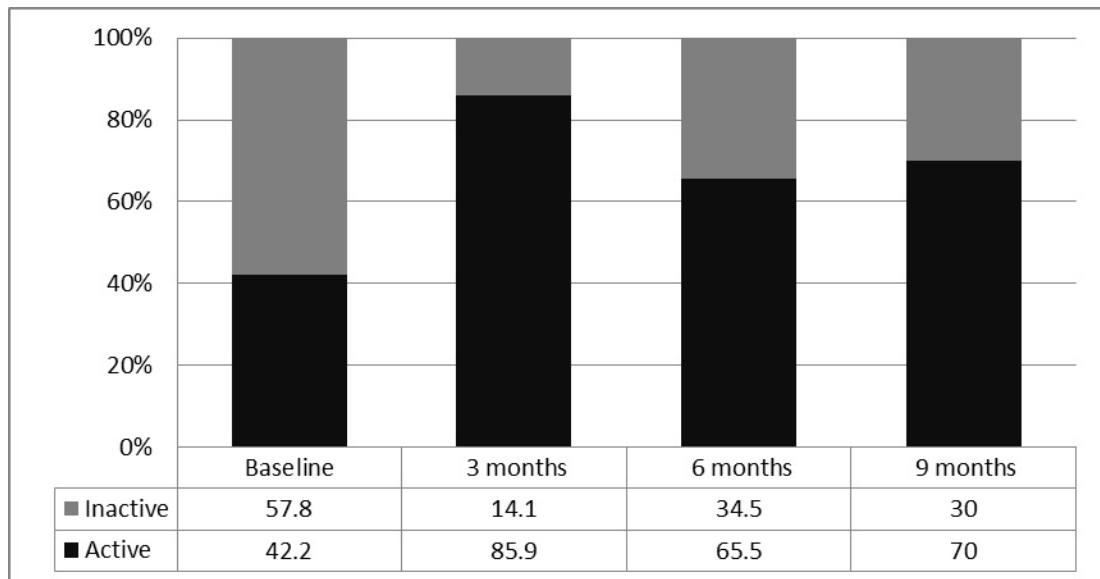


Figure 4.6. Proportion of active and inactive individuals over four assessment periods: baseline (N=64) and follow-ups at three months (immediately after intervention, N=64), six months (N=61), and nine months (N=40). Values expressed in percentages (%).

Box-plots representing the rate of change in the total sample of active and inactive individuals with SCI (N = 64 at baseline and three months; n = 61 at six months; and n = 40 at nine months) over each period is shown in **Figure 4.7**. Mean and standard deviation (SD) values were selected to express the average time engaged in physical activity due to the normal distribution of data. Nevertheless, median and interquartile range (IQR) values are also presented on **Table 4.2** to account for the non-parametric distribution of LTPA presented by the active and inactive groups.

The median time involved in LTPA at baseline increased from 19.8 (IQR 0 to 60) minutes to 60 (IQR 32.5 to 70.0) minutes after three months of intervention. During the follow-up periods, the median remained higher than baseline values with 40 (IQR 21.6 to 65) minutes at six months and 47.5 (IQR 25.8 to 70.8) minutes at nine months. Improvements in LTPA levels were significant in all assessment periods compared to baseline as shown on **Table 4.3**. Differences between baseline compared to follow-up values were more prominent at the end of SCIPA Com (three months), with an increase of 26 (95%CI: 16.6 to 35.4; $P < .001$) minutes of LTPA per day. Follow-up assessments after six and nine months also obtained improvements of 15.2 (95%CI: 5.8 to 24.6; $P < .001$) and 20.1 (95%CI: 5.5 to 34.6, $P < .01$) minutes of LTPA per day, respectively. Differences between three and six months (-10.4, 95%CI: -19.2 to 7.3, $P = .083$), and six and nine months (4.4, 95%CI: -10.7 to 19.7, $P = .565$) were not significant.

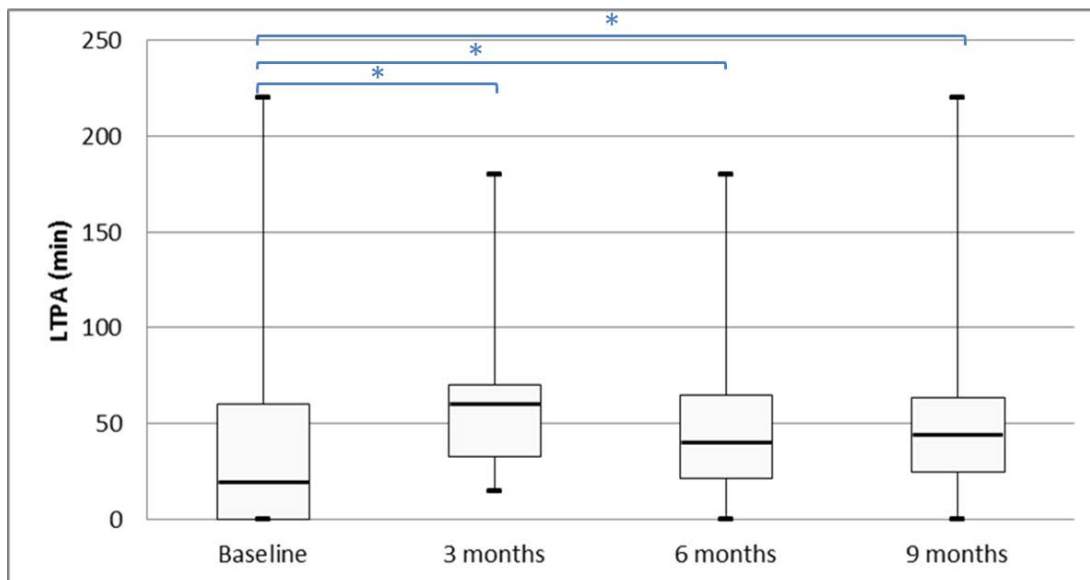


Figure 4.7. Changes in leisure time physical activity (LTPA) levels over four assessment periods: baseline (N=64) and follow-ups at three months (immediately after intervention, N=64, 27 active and 37 previously inactive), six months (N=61, 27 active and 24 previously inactive), and nine months (N=40, 20 active and 20 previously inactive). Values expressed as median (bold horizontal line), interquartile range (boxes), minimum and maximum values (whiskers). Note. blue * $P < .001$ (significant increase in LTPA)

There was a main effect for LTPA levels ($P < .001$) and interaction effects between time and LTPA levels ($P < .001$).

Table 4.2. Moderate and heavy leisure time physical activity over time (values expressed in minutes)

	Clients with SCI (N=64)					
	Total (N=64)		Inactive (n=37)		Active (n=27)	
	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)
Baseline	32.5 (41.7)	19.8 (0 to 60)	4.6 (8.5)	0 (0 to 10)	70.8 (38.9)	60 (48 to 80)
3 months	58.6 (32.4)*	60 (32.5 to 70)*	46.6 (22.0)*	45 (30 to 60)*	75.1 (37.4)	62.6 (56.6 to 90)
6 months	48.2 (40.6)*	40 (21.6 to 65)*	35.5 (37.6)*	26.6 (0 to 55.6)*	64.2 (39.0)	53.3 (40 to 81.6)
9 months	52.7 (41.2)*	47.5 (25.8 to 70.8)*	37.9 (49.4)*	27.3 (7.5 to 42.5)*	67.4 (24.3)	60 (52.5 to 80.1)

Note. Mean and standard deviation (SD) of leisure time physical activity (LTPA) in minutes (min); Interquartile Range Q1 to Q3 (IQR); and probability (*P*) values compared to baseline. **P* <.001

Table 4.3. Moderate and heavy leisure time physical activity during baseline period compared to follow-up periods (values expressed in minutes).

	Baseline	3 months		6 months		9 months	
	Mean LTPA (SE)	Difference (95%CI) (min)	<i>P</i>	Difference (95%CI) (min)	<i>P</i>	Difference (95%CI) (min)	<i>P</i>
Total (N=64)	32.5 (4.4)	26.0 (16.6, 35.4)	.001*	15.2 (5.8, 24.6)	.001*	16.9 (8.1, 25.8)	.001*
Inactive (n=37)	4.6 (2.5)	41.9 (33.7, 50.1)	.001*	31 (21.8, 40.2)	.001*	33.1 (18.7 to 47.6)	.001*
Active (n=27)	70.8 (5.5)	4.3 (-10.9, 19.6)	.579	-6.5 (-21.8, 8.7)	.400	-3.2 (-18.6 to 12.13)	.680

Note. Mean and standard error (SE) of leisure time physical activity (LTPA) in minutes (min) at baseline; LTPA difference (Diff) in minutes (min) compared to baseline; 95% confidence interval; and probability (*P*) values compared to baseline. **P* <.001

In order to ratify the theory that individuals considered previously active or inactive would respond to physical activity in different magnitudes, further analysis required the dichotomisation of individuals with SCI into two groups for separate analysis. The division of the total population into sub-cohorts of active (n=27) and inactive (n=37) clients with SCI were necessary to observe changes especially in the inactive portion of participants and determine if they achieved the minimal target of 30 minutes of LTPA per day. Distinct changes in LTPA levels were evident by analysing these two groups separately at each time point, as shown in **Figure.4.8**. Greater improvements were obtained in the inactive cohort compared to the active population, which maintained LTPA levels over time.

Initially, 75% of the inactive group had LTPA of less than 10 min per day (the median value of LTPA zero, IQR 0 to 10). As expected, the median LTPA increased to 45 (IQR 30 to 60) minutes after intervention (three months). Median LTPA decreased in follow-up periods of six (26.6, IQR 0 to 55.6 minutes) and nine months (27.3, IQR 7.5 to 42.5 minutes) compared to baseline. Differences in time compared to baseline among the inactive cohort ranged from 41.9 (95%CI: 33.7 to 50.1; $P < .001$) immediately after intervention (3 months), to 31 (95%CI: 21.8 to 40.1; $P < .001$) at six months, and 33.1 (95%CI: 18.7 to 47.6; $P < .001$) at nine months. Differences between three and six months showed a significant reduction of LTPA (-10.8, 95%CI: -20.5 to -1.2), whereas no differences were detected between six and nine months (2.8, 95%CI: -9.1 to 14.8, $P = .646$)

The variation was smaller in the active group, with chronological median values of 60 (IQR 48 to 80) minutes, 62.6 (IQR 56.6 to 90) minutes, 53.3 (IQR 40 to 81.6) minutes, and 60 (IQR 46.6 to 80.3) minutes of LTPA per day over the four assessments. In the post-intervention period (three months), the active group showed a non-significant increase of 4.3 (95%CI: -10.9 to 19.6; $P = .579$) minutes compared to baseline. LTPA levels were slightly below baseline values in follow-up periods of six (-6.5, 95%CI: -21.8 to 8.7; $P = .400$) and nine months (-3.2, 95%CI: -18.6 to 12.13; $P = .680$), though values were again not statistically different. Differences between three and six months (-10.9, 95%CI: -26.4 to 4.6, $P = .170$), as well as six and nine months (.4, 95%CI: -13.8 to 14.6, $P = .955$) were not significant either.

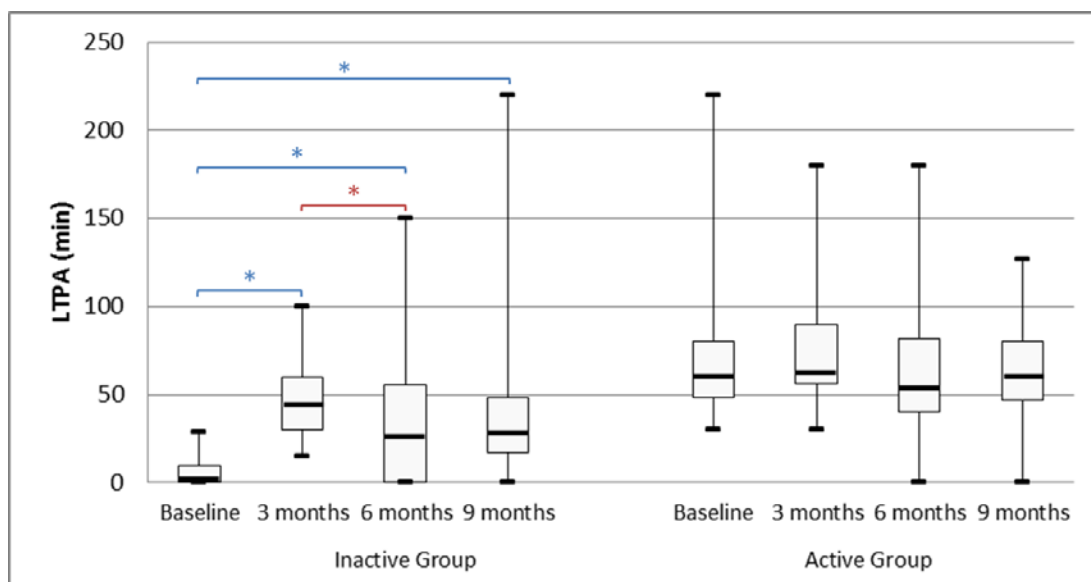


Figure 4.8. Changes in leisure time physical activity (LTPA) levels over four assessment periods in the Inactive (n=37) and Active Groups (n=27). Values expressed as median (bold horizontal line), interquartile range (boxes), minimum and maximum values (whiskers). Note. blue* $P < .001$ (significant increase in LTPA); red* $P < .05$ (significant reduction in LTPA).

4.7.3 Functional goal achievement outcomes

Clinical (changes greater than 1.2 points) and statistical improvements were also obtained with functional goal achievement outcomes. As displayed in **Figure 4.9**, combined scores of inactive and active groups increased from 4.3 (SE .12) at baseline to 6.3 (SE .10), 6.1 (SE .09), and 6.1 (SE .15) after three, six, and nine months respectively. Significant clinical and statistical differences between follow-up and baseline scores ranged from 2.0 (95%CI: 1.7 to 2.3; $P < .001$), 1.8 (95%CI: 1.5 to 2.1; $P < .001$), to 1.8 points (95%CI: 1.4 to 2.2; $P < .001$) in order of assessments periods.

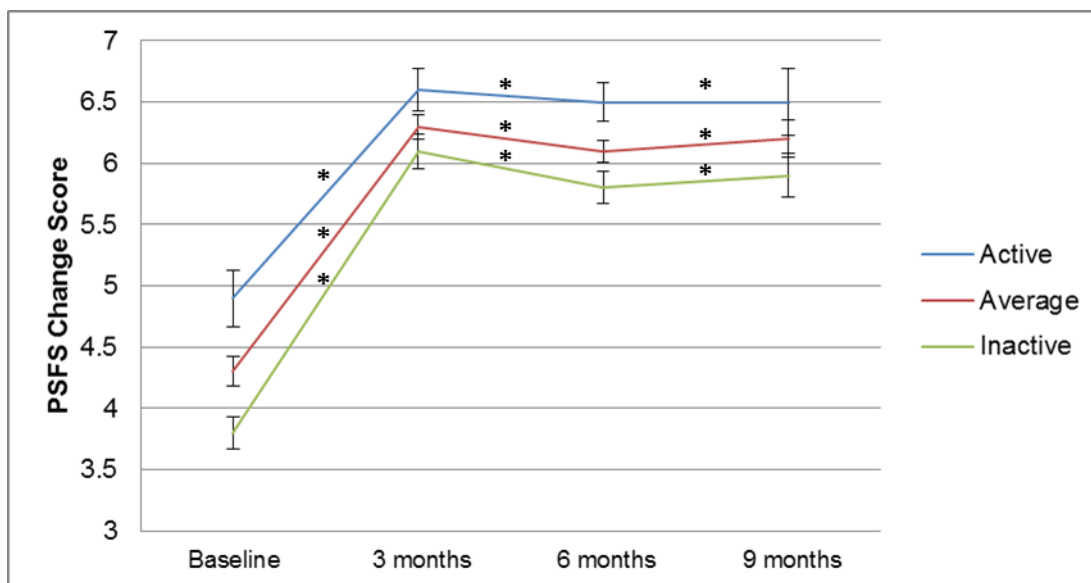


Figure 4.9. Changes in functional goal achievement scores on the Patient Specific Functional Scale (PSFS) over four assessment periods for the total group and active and inactive subgroups. Values expressed as mean and standard error. * $P < .05$ compared to Baseline scores.

Larger improvements were seen in the inactive group which began the program with a 3.8 (SE .13) average score, increasing to 6.1 (SE .14) and 5.8 (SE .13), before finishing with 5.9 (SE .18) at nine months. The differences from baseline were most prominent in the post-intervention period (3 months) with a 2.3 (95%CI: 1.9 to 2.6; $P < .001$) average score difference, followed by similar score differences at six (2.0, 95%CI: 1.6 to 2.3; $P < .001$) and nine months (2.0, 95%CI: 1.6 to 2.5; $P < .001$). Changes following the intervention were maintained with no significant changes detected between months three and six (-.27, 95%CI: -0.66 to 0.11; $P = .170$) and between months six and nine (-.24, 95%CI: -.70 to 0.20; $P = .286$).

The active group also presented average score increases in follow-up periods (6.6, SE .17 at three months; 6.5, SE .16 at six months; 6.5, SE .27 at nine months) compared to baseline (4.9, SE .23). Differences were clinically and statistically significant at three (1.6, 95%CI: 1.2 to 2.2; $P < .001$), six (1.5, 95%CI: 1.1 to 2.0; $P < .001$), and nine (1.5, 95%CI: 1.1 to 2.1; $P < .001$) months follow-up assessments. The six months (-.17, 95%CI: -0.6 to 0.3; $P = .484$) assessments were not significantly different compared to the score at three months; nor were differences at nine months (0.03, 95%CI: -0.61 to .67; $P = .920$) compared to six months.

There was a main effect for time ($P < .001$), a main effect for LTPA levels at baseline ($P < .001$), but no significant interaction effect between time and LTPA levels ($P = .255$). Differences between groups ran in parallel until the final assessment, when results were similar in both groups.

4.7.4 Self-esteem outcomes

There was a main effect for time ($P < .001$) and a main effect for LTPA levels at baseline ($P < .01$), though without significant interaction effect between time and LTPA levels at baseline ($P = .110$).

Self-esteem scores increased in all three follow-up periods compared to baseline (20.6, SE .31). These scores rose to 22.1 (SE .22) in the three months follow-up period, 22 (SE .23) at six months, and 21.5 (SE .35) at nine months. The difference from baseline was similar in follow-up periods of three (1.5, 95%CI: 0.72 to 2.27; $P < .001$) and six months (1.4, 95%CI: 0.68 to 2.16, $P < .001$), and not significant at the nine months mark (.77, 95%CI: -.16 to 1.7, $P = .107$). The inactive group presented lower self-esteem scores throughout most assessment; however, they presented a higher mean in their last assessments compared to baseline scores. Self-esteem scores in the inactive group ranged from 19.7 (SE .45) at baseline, 21.4 (SE .32) at three months, 21.5 (SE .38) at six months, to 21.5 (SE .51) at nine months follow-ups. During the same period, the active group improved scores from 21.7 (SE .49), to 23 (SE .44) and 22.8 (SE .48), before regressing to 21.4 (SE .58) in the final assessment. The developments of self-esteem scores for both groups are presented in **Figure 4.10**.

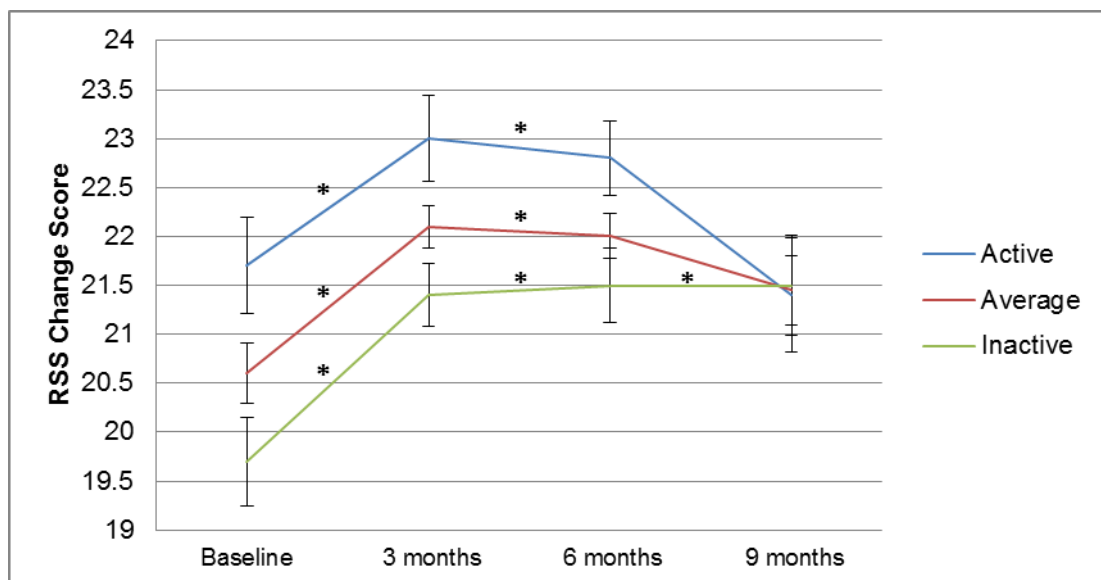


Figure 4.10. Changes in self-esteem scores over four assessment periods on the Rosenberg Self-Esteem Scale (RSS) for the total group and active and inactive subgroups. Values expressed as mean and standard error. * $P < .05$ compared to Baseline scores.

Total group (N = 64) differences between follow-up scores compared to baseline were significant ($P < .05$) in all assessments, with the exception of the nine months follow-up ($P = .655$). The inactive group improved at every time point, starting with a 1.6 (95%CI: 0.6 to 2.7; $P < .01$) difference from baseline at three months, progressing to 1.7 (0.58 to 2.8; $P < .01$) at six months and finishing the assessments with 1.7 (95%CI: 0.39 to 3.1; $P < .05$) average score difference. There was a slight increase of 0.4 (95%CI: -0.85 to 0.95; $P = .918$) between three and six months and 0.10 (95%CI: -1.0 to 1.2; $P = .856$) between six and nine months, though differences were non-significant. Scores gradually increased in the active group as well. At three months, scores were 1.6 (95%CI: 0.6 to 2.7; $P < .05$) points higher than baseline, reducing to 1 (95%CI: 0.01 to 2; $P < .05$) at six months, with no significant changes at nine months (-0.30, 95%CI: -1.6 to 1.0; $P = .657$). Though not statistically significant, differences in scores decreased overtime comparing three and six months (-0.22, 95%CI: -1.1 to 0.71; $P = .641$) and six and nine months' scores (-1.3, 95%CI: -2.5 to -0.10; $P = .033$).

4.7.5 Quality of life outcomes

Quality of life total results differed according to the domain analysed. There was a main effect for time ($P < .001$) in the psychological and environmental domains, indicating an improvement in these domains over time. A significant main effect for LTPA levels at baseline in the social ($P < .05$) and environmental ($P < .01$) domains suggested a positive influence of LTPA over social and environmental aspects of quality of life. Finally, interaction effects between time and LTPA levels at baseline in the psychological domain ($P < .001$) demonstrated improvements in psychological domain due to increased LTPA over time.

Significant improvements ($P < 0.5$) were obtained in all three follow-up assessments with the exception of the physical domain at six months and overall quality of life and health at nine months. The numeric results obtained for quality of life measures are displayed on **Table 4.4**. The environmental domain presented the best scores in all four assessment periods. Differences between baseline scores and the following evaluations were greater in the psychological domain compared to environmental. The social domain increased especially in the three months evaluation and maintained improvements in months six and nine.

Table 4.4. Secondary health outcomes scores during baseline compared to follow-up periods.

Total (n=64)	Baseline	3 months			6 months			9 months		
	Mean (SE)	Mean (SE)	Diff (95%CI)	P	Mean (SE)	Diff (95%CI)	P	Mean (SE)	Diff (95%CI)	P
Quality of Life										
Overall Qol	13.5 (.24)	14.7 (.20)	1.21 (.56, 1.8)	<.001*	14.2 (.20)	.74 (.05, 1.4)	.035**	13.9 (.31)	.40 (-.4, 1.2)	.328
Physical	13.1 (.16)	14.1 (.14)	.99 (.55, 1.4)	<.001*	13.3 (.14)	.21 (-.02, .64)	.339	13.6 (.16)	.52 (.07,.97)	.021**
Psychological	13.6 (.27)	14.5 (.23)	.90 (.17, 1.6)	.016**	15.1 (.27)	1.4 (.70, 2.2)	<.001*	15.1 (.43)	1.5 (.53, 2.5)	.002**
Social	13.1 (.20)	13.8 (.15)	.68 (.20, 1.1)	.005**	13.7 (.15)	.64 (.15, 1.1)	.01**	13.7 (.21)	.58 (.01, 1.1)	.045**
Environmental	14.9 (.16)	15.4 (.13)	.58 (.16, .99)	.006**	15.5 (.12)	.65 (.24, 1.0)	.002**	15.8 (.17)	.91 (.46, 1.3)	<.001*
Self-esteem	20.6 (.31)	22.1 (.22)	1.5 (.72, 2.2)	<.001*	22.0 (.23)	1.4 (.68, 2.1)	<.001*	21.4 (.35)	.77 (-.16, 1.7)	.107
Functional Goal Achievement	4.3 (.12)	6.3 (.10)	2.0 (1.7, 2.3)	<.001*	6.1 (.09)	1.8 (1.5, 2.1)	<.001*	6.1 (.15)	1.8 (1.4, 2.2)	<.001*

Note. Mean and standard error (SE) of scores over time; score difference (Diff) compared to baseline and 95% confidence interval (CI); probability (P) values compared to baseline; Quality of life (Qol).

*P <.001, **P <.05

Increases in the overall quality of life and physical domain were evident at three months follow-up, though most participants did not maintain improvements at six and nine months and regressed to scores similar to baseline measures. There was a main effect for LTPA levels at baseline in the overall and physical ($P < .001$) domains, demonstrating an improvement in these two domains as a result of increased LTPA levels. An interaction effect between time and LTPA levels at baseline in the overall domain ($P < .001$) showed an improvement in overall quality of life over time due to increased LTPA. No main effect for time alone in the overall ($P < .557$) and physical domain ($P = .139$) were encountered. A summary of all quality of life domains' tendencies over time in the total group are displayed in **Figure 4.11**

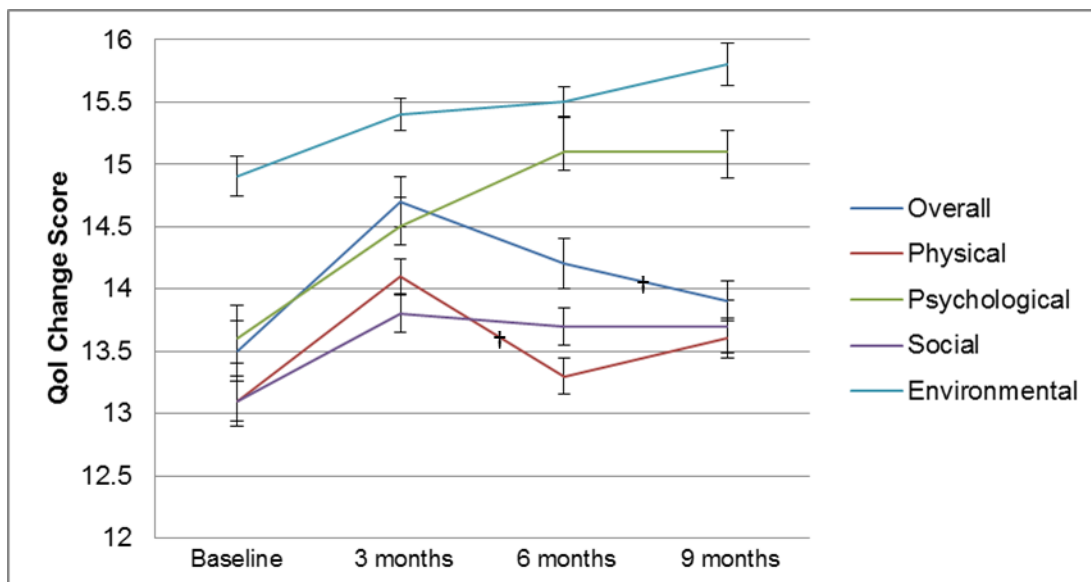


Figure 4.11. Changes in different domains of quality of life scores over four assessment periods for the **total group**. Values expressed as mean and standard error. Differences in scores were statistically significant, with the exception of scores in the physical domain between three and six months, and in the overall domain between six and nine month ($^{\dagger}P > .05$ compared to Baseline scores).

The average increase in quality of life domains scores in the inactive group was larger during follow-up assessments, whereas scores presented by the active group were consistent throughout virtually every assessment period. The inactive group had significant improvements ($P < .05$) in all follow-up periods for the five different quality of life domains, with the exception of social relationship in the three ($P = .120$) and nine months follow-ups and ($P = .131$) and physical health in the six ($P = .121$) and nine months follow-ups ($P = .052$) (refer to **Figure 4.12**).

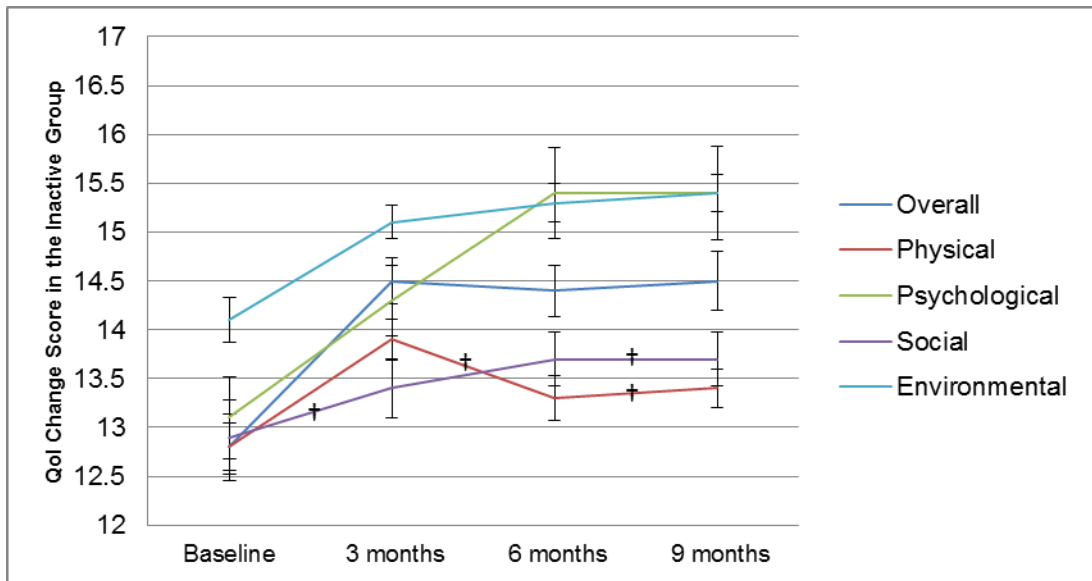


Figure 4.12. Changes in different domains of quality of life scores over four assessment periods for the **inactive group**. Values expressed as mean and standard error. Differences in scores were statistically significant, with the exception of scores in the physical domain between three and six months, and in the overall domain between six and nine month ($^{\dagger}P > .05$ compared to Baseline scores).

In contrast, follow-up assessments in the active group revealed very little change in quality of life compared to baseline values, other than increased physical ($P < .05$) and psychological ($P < .01$) health at three months follow-up (refer to **Figure 4.13**). A detailed summary of all secondary outcome scores in the active and inactive groups are presented on **Table 4.5**.

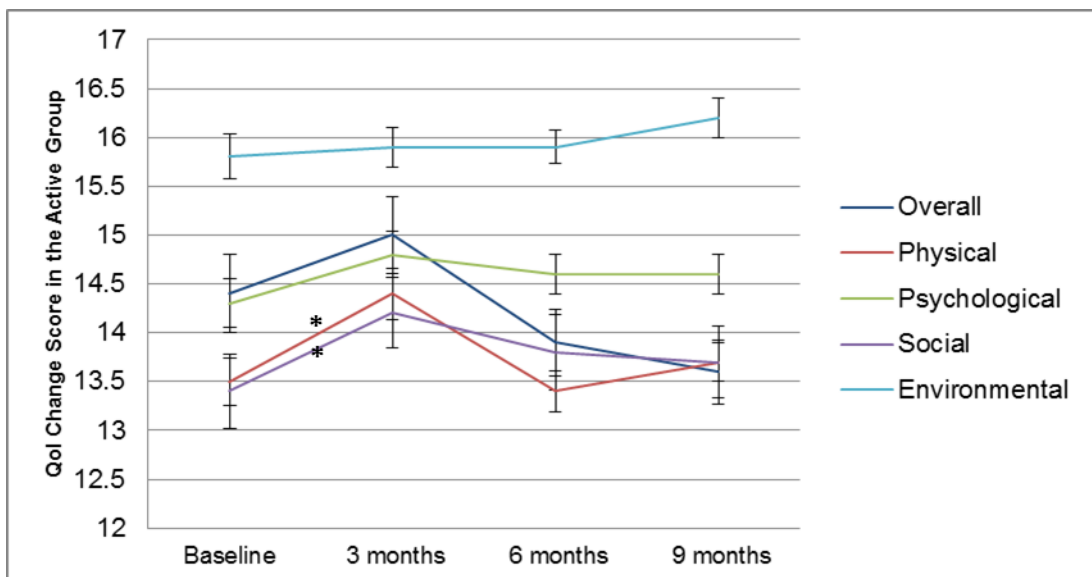


Figure 4.13. Changes in different domains of quality of life scores over four assessment periods for the **active group**. Values expressed as mean and standard error. * $P < .05$ compared to Baseline scores.

Table 4.5. Secondary health outcomes scores during baseline compared to follow-up periods in the inactive group and active group.

Inactive (n=37)	Baseline	3 months			6 months			9 months		
	Mean (SE)	Mean (SE)	Diff (95%CI)	P	Mean (SE)	Diff (95%CI)	P	Mean (SE)	Diff (95%CI)	P
Quality of Life										
Overall Qol	12.8 (.34)	14.5 (.24)	1.6 (.8, 2.5)	<.001*	14.4 (.26)	1.6 (.8, 2.5)	<.001*	14.5 (.44)	1.7 (.6, 2.7)	.002**
Physical	12.8 (.24)	13.9 (.21)	1.12 (.5, 1.7)	<.001*	13.3 (.23)	.50 (-.1, 1.1)	.121	13.5 (.26)	.68 (-.01, 1.3)	.052
Psychological	13.1 (.42)	14.3 (.36)	1.2 (.1, 2.4)	.050**	15.4 (.47)	2.2 (1, 3.5)	<.001*	15.7 (.83)	2.6 (.7, 4.4)	.006**
Social	12.9 (.38)	13.4 (.3)	.58 (-.1, 1.3)	.120	13.7 (.28)	.81 (-.1, 1.5)	.024**	13.5 (.38)	.66 (-.1, 1.5)	.131
Environmental	14.1 (.23)	15.1 (.17)	.99 (.4, 1.5)	<.001*	15.3 (.2)	1.1 (.5, 1.7)	<.001*	15.4 (.28)	1.2 (.5, 2)	.001*
Self-esteem	19.7 (.45)	21.4 (.32)	1.6 (.6, 2.7)	.002**	21.5 (.38)	1.7 (.5, 2.8)	.003**	21.5 (.51)	1.7 (.3, 3.1)	.01**
Functional Goal Achievement	3.8 (.13)	6.1 (.14)	2.3 (1.9, 2.6)	<.001*	5.8 (.13)	2 (1.6, 2.3)	<.001*	5.9 (.18)	2 (1.6, 2.4)	<.001*
Active (n=27)										
Quality of Life										
Overall Qol	14.4 (.4)	15.0 (.39)	.56 (-.5, 1.6)	.308	13.9 (.34)	-.47 (-1.4, .5)	.348	13.4 (.41)	-1 (-2.1, .03)	.057
Physical	13.5 (.24)	14.4 (.26)	.82 (.1, 1.4)	<.011**	13.4 (.21)	-.17 (-.7, .4)	.573	13.9 (.24)	.32 (-.2, .9)	.305
Psychological	14.3 (.25)	14.8 (.24)	.49 (-.1, 1.1)	.115	14.6 (.20)	.36 (-.1, .9)	.188	14.6 (.25)	.30 (-.3, .9)	.364
Social	13.4 (.38)	14.2 (.36)	.82 (.2, 1.4)	.006**	13.8 (.39)	.43 (-.2, 1)	.199	13.8 (.41)	.48 (-.1, 1.1)	.153
Environmental	15.8 (.23)	15.9 (.2)	.01 (-.5, .6)	.954	15.9 (.17)	.03 (-.5, .5)	.891	16.3 (.24)	.43 (-.16, 1)	.157
Self-esteem	21.7 (.49)	23 (.44)	1.2 (.1, 2.3)	.027**	22.8 (.38)	1.0 (.01, 2)	.047**	21.4 (.58)	-.30 (-1.6, 1)	.657
Functional Goal Achievement	4.9 (.23)	6.6 (.17)	1.6 (1.1, 2.2)	<.001*	6.5 (.16)	1.5 (1, 2)	<.001*	6.5 (.27)	.92 (1.1, 2.1)	<.001*

Note. Mean and standard error (SE) of scores over time; score difference (Diff) compared to baseline and 95% confidence interval (CI); probability (P) values compared to baseline; Quality of life (Qol).

*P <.001, **P <.05

4.8 DISCUSSION

SCIPA Com participants presented improved LTPA levels, leading to increased functional satisfaction, quality of life and self-esteem by the end of eight-to-twelve weeks of training; results which support our initial hypothesis. These improvements were more evident among the previously inactive SCI population. As anticipated, the total group maintained higher levels of LTPA over time compared to baseline; this change was once again enhanced among the previously inactive group.

Safety and accessibility to LTPA in the community setting for individuals with SCI also improved. The process consisted of two phases. Phase one provided community capacity building, fitness centre engagement, and support for exercise professionals in delivering services to the SCI population. Phase two led to the implementation of physical activity programs, customised for each client according to their personality attributes (refer to **Chapter 5**), physical strengths, and goals. This study resulted in significant improvements for LTPA participation and additional important health outcomes.

The SCIPA Com program is in line with Rimmer and Henley's (2013) work developed in community fitness centres. These authors corroborated the utility of fitness centres due to their suitable installations, equipment, and supportive environments for the promotion of physical activity. Similar to the present study, several other community-based programs increased physical activity uptake with the provision of educational material on the subject and supervision (Block et al., 2010; Froehlich-Grobe et al., 2012; Pelletier, 2014; Warm, Belza, Whitney, Mitchell, & Stiens, 2004). Further common findings were increased exercise efficiency, reduced costs and time travelling to distant locations. However, SCIPA Com was the first to verify the effectiveness of fitness centres and exercise professionals readily available in a variety of locations, as opposed to specialised facilities for individuals with physical disabilities (Rimmer & Henley, 2013), university campuses (Warm et al., 2004), or home-based programs (Block et al., 2010; Froehlich-Grobe et al., 2012; Pelletier, 2014; Wise et al., 2009).

The number of participants with SCI in SCIPA Com revealed an important demand for physical activity opportunities in community-based facilities after discharge from rehabilitation services. This statement is supported by previous studies reporting high attendance rates in health promotion initiatives such as SCI

Action Canada and *SCI Ontario* events (N = 140 health professionals) (Gainforth et al., 2014), *Project Work Out on Wheels* (N = 135 wheelchair users) (Froehlich-Grobe et al., 2014), and *Project Shake-It-Up* (N = 26 neurological patients) (Block et al., 2010). Results from the aforementioned Canadian program showed similar uptake rates (88%) compared to SCIPA Com (82%). Both programs confirmed the potential of community-based-organisations in the promotion of knowledge among service providers regarding physical activity guidelines and programs for people with SCI (Gainforth et al., 2014; Martin Ginis et al., 2012i). Improved outcomes were obtained via such collaborations between university researchers and reputable community partners. They combined expertise and evidence based-practice with already established organisations (Martin Ginis et al., 2012i).

The elevated number of exercise professionals that did not follow through with the *T3-SCI®* course indicated difficulties associated to the engagement of service providers in community fitness centres. Exercise professionals had the autonomy to complete the online training course at their convenience, which was a different approach compared to that adopted by *SCI Action Canada* and *SCI Ontario* events (Gainforth et al., 2014). Perhaps the organisation of events with an established time frame and with the participation of a larger cohort in the community could be an incentive to increase participation.

The process conducted to close the gap between institutionalised health care (i.e. hospital and clinics) and optimal health maintenance in the community was successful through the implementation of an organised referral system (refer to **Appendix 7**) and tailored physical activity programs. Collaborations with renowned organisations such as the YMCA and council-run fitness centres are supported by evidence (Elley et al., 2007; Moore et al., 2011; Pelletier et al., 2014; Rimmer & Henley, 2013; Sheehy, 2013; Williams et al., 2007), yielding in increased LTPA levels in SCIPA Com clients. The effectiveness of supervision by staff members with SCI clientele in previous studies had controversial results in favour of supervised interventions (Froehlich-Grobe et al., 2014) or self-guided measures (Wise et al., 2009). In the general population, exercise professionals have shown to revert low adherence rates (Moore et al., 2011; Williams et al., 2007) and their background knowledge on health and fitness placed them at an advantage to learn through *T3-SCI®* how to adapt pre-existing skills for clients with SCI. Therefore, exercise professionals played a fundamental role in SCIPA Com's adherence rates.

Prior to their involvement in SCIPA Com, most exercise professionals reported virtually no experience working with clients with high levels of disability. Interestingly,

this was not a deterrent during the program regarding the development and execution of effective physical activity programs for clients with SCI. The accumulated experience gained by working with SCIPA Com and additional clients with SCI may lead to even more benefits in the future. Exercise professionals received educational and logistics support from our researchers and were able to secure clients from injuries; though there was one case of rotator cuff re-injury in a participant from the active group during week 11. Excessive weight-training was determined as the cause, highlighting the importance of caution whilst training SCI populations predisposed to shoulder injuries, even when considered active (covered in **Appendix 6: T3-SCI®**, Unit 4 - Clinical and Medical Considerations, page 23) (Fullerton et al., 2003; Nash, 2005). Further precautions were emphasised in *T3-SCI®*, especially regarding autonomic dysfunctions in people with SCI.

One of the key features of this study was its ecological validity on the basis that it introduced community dwelling adults with SCI to exercise professionals new to adapted training. Previous community-based studies have counted with health-allied professionals (e.g. nurses) (Sheehy, 2013) or highly educated researchers to conduct interventions. Though qualified health professionals help ensure the quality of physical activity programs, their labour often comes at an increased cost compared to those of exercise professionals and presents reduced translational value. As proposed by Sevick et al. (2000), interventions executed by trained exercise professionals via SCIPA Com reduced costs (refer to **Chapter 3** under **3.8 Discussion**), with an added advantage of making these services available to others in the community.

Regarding the population studied in SCIPA Com, their demographic and injury characteristics were similar to Australia's national SCI average in age (approximately 47 years of age), gender distribution (81% male), and SCI classification (34% incomplete tetraplegia, 25% incomplete paraplegia, 25% complete paraplegia, and 16% complete tetraplegia) (Cripps, 2009; Cripps et al., 2011). The proportion of traumatic cases of SCI (81%) in SCIPA Com's cohort was higher compared to the local and international average (approximately 60% traumatic causes world-wide) (New et al., 2013; O'Connor, 2005c). There may be an association between traumatic injuries and typical action-driven and risk-taking personality of a person with SCI (Rohe & Krause, 1999). Hence, though having an extroverted trait increases the risk of SCI (Griffiths et al., 2012), it also may have been an advantage for the uptake of physical activity among participants.

Studies have stated divergent results pertaining the influence of demographic differences on physical activity behaviour (Kim et al., 2011; Martin Ginis et al., 2010e), though our findings agree that gender and lesion characteristics moderate physical activity fitness (Janssen et al., 1994; Latimer et al., 2006j). Within the cohort analysed in this study, significant differences in gender distribution and cause of SCI were observed between the inactive and active groups at baseline measures as well. Men were over five times more likely to be active at baseline ($P < .001$) and the active group presented almost five times more chances of having a traumatic SCI compared to the inactive group ($P < .001$). Once again, this corroborates with a study which stated that men with SCI are more likely to be active due to gender role activities (such as physical tasks), having further interest in sports, being more competitive/risk-taking, and receiving better social support to engage in physical activity (Rauch et al., 2013). The fact that only individuals in the inactive group made use of the electric wheelchairs also suggests that the severity of the injury may be associated to physical activity participation.

Likewise, advanced age (DeVivo & Chen, 2011) may be a confounding factor that leads to inactivity, considering that most non-traumatic cases of SCI in Australia are among people over 45 years of age (New et al., 2013). Though not significant, the inactive group presented a higher number of individuals with complete tetraplegia, which is not surprising given that level and completeness of SCI have been found to be the strongest predictors for functional independence (Teeter et al., 2012).

Regardless of differences at baseline, the SCI population presented significant improvements in all health outcome measures after receiving support from SCIPA Com and their local community fitness centres. Immediately following the intervention period, participants surpassed the recommended physical activity levels established by evidence based clinical guidelines for improved fitness (20 min/day of moderate to heavy LTPA) (Martin Ginis et al., 2011a), and standards set by the ACSM and Physical Activity Guidelines for Americans in people with chronic disabilities. The average improvement in LTPA was remarkably higher in this study post-intervention (26 min/day \approx 182 min/week) compared to other programs that included people with SCI (between 17 and 155 min/week) (Brawley et al., 2013; Froehlich-Grobe et al., 2014; Wise et al., 2009). A difference was expected since 42.2% of our participants already engaged in high levels of physical activity prior to intervention (increasing the total LTPA average in all assessments), whereas the aforementioned studies included mainly inactive individuals.

Some have argued that retrospective self-reported assessment instruments overestimate activity levels (Matthews, Moore, George, Sampson, & Bowles, 2012; Sallis & Saelens, 2000). However, Tanhoffer et al. (2012) proved adequate internal reliability for the PARA-SCI tool. We also considered reporting median and interquartile range values for comparisons to ensure the closest representation of the central tendency score. Most community training studies have used mean and standard deviations to report physical activity, which can be interpreted as a limitation since values were largely skewed (observed in the large standard deviation numbers relative to the mean). Consequently, non-parametric data presented as mean and standard deviations may have overestimated the cohort central tendency.

Higher LTPA levels recorded especially after SCIPA Com intervention period (three months follow-up) may further be attributed to components of the program, such as proximity to fitness centres, community integration, and sense of commitment with the exercise professionals. These measures were identified and adopted according to our participants needs, as described in *Study 1* (refer to **Chapter 3**). Physical activity programs were individually tailored and measures that facilitated access to fitness centres were provided whenever possible. This tactic has shown to be effective because they align plans with the patient's expectations and capabilities (Elley et al., 2007).

As observed by other authors (Froehlich-Grobe et al., 2014; Wise et al., 2009), follow-up assessments revealed similar deceleration patterns in LTPA levels once interventions ceased. Though not measured in the present study, researchers have attributed this decline in physical activity due to issues with participant self-management (i.e., having the intention to exercise and planning sessions) and self-efficacy following their involvement in structured training programs (McAuley et al., 2011; Shields & Brawley, 2006). In *Study 1* (refer to **Chapter 3**) financial constraints and lack of motivation were identified as important factors in reducing LTPA levels over time.

The intervention also led to improved functional satisfaction among SCIPA Com participants in all follow-up periods. The underlying mechanisms of regular physical activity, including greater strength and power output (Ditor et al., 2003; Froehlich-Grobe et al., 2014; Hicks et al., 2003; Wise et al., 2009) are potentially linked to improved function, though further studies are necessary to determine their association.

Greater quality of life and psychosocial improvements attained in this study's SCI population were similar to previous studies. Ditor et al. (2003) and Hicks et al. (2003) found significant increased quality of life measures in response to a nine month resistance training protocol in the laboratory setting; whereas participants in SCIPA Com presented enduring improvements after eight-to-twelve weeks of intervention. The importance of physical activity was further highlighted by a large cohort study (n = 357,665) in populations with and without physical and psychological limitations, which demonstrated a direct correlation between recommended physical activity levels and lower odds ratio of having poor health related quality of life (Brown, Carroll, Workman, Carlson, & Brown, 2014; Brown et al., 2004). Initial assessments in SCIPA Com had already indicated better quality of life among the active group before SCIPA Com, as did a cross-sectional study involving 264 individuals with chronic SCI (Anneken et al., 2010).

This study's cohort presented better baseline quality of life measures in every domain (physical: 13.1, SD 2.6; psychologic: 13.1, SD2.6; social: 13.1, SD 2.9; environment: 14.9, SD 2.6) compared to scores reported by a previous study (physical: 11.4, SD 2.8; psychologic: 11.7, SD 2.7; social: 12.5, SD 2.6; environment: 12.2, SD 2.6) in Taiwan (Jang et al., 2004). Even when analysing the inactive population separately (physical: 12.8, SD 2.7; psychologic: 13.2, SD 3.2; social: 13, SD 3.2; environment: 14.2, SD 2.5) scores remained higher than those reported by Jang et al. (2004). Another cross-country study utilising WHOQOL-BREF did not find significant differences between quality measures in Australian people with SCI compared to five other nations, though Brazil and Israel presented significantly lower scores compared to the United States (Geyh et al., 2013).

Differences concerning quality of life can be explained by the elevated socioeconomic status of our study's cohort and location, often ranked among the world's top countries in quality of living (Glatzer, 2012). The *United Nations 2013 Human Development Report* ranked Australia number two and New Zealand number six in health, education, social integration, gender equality, environment, innovation and technology, and other indicators world-wide (The United Nations, 2013). The population in the present study had sustained their SCI for long periods of time (over nine years in average), which has been positively related to increased quality of life by several researchers (Dijkers & Zanca, 1999; Geyh et al., 2013; Kreuter, Siösteen, Erholm, Byström, & Brown, 2005).

Improvements in quality of life were especially high in the inactive group, which produced significant differences in most domains, as well as self-esteem, and

functional goal achievement scores, while the active group maintained high quality of life scores throughout evaluations. Interestingly, improvements in the total population were not significant at six months ($P = .339$) for the physical quality of life domain. This finding contradicts average functional goal achievement score advances ($P < .001$), but perhaps highlights the impact of psychological benefits. Physical activity is known to enhance psychological well-being, self-efficacy, and social engagement, which may have reflected in physical and functional satisfaction (Anneken et al., 2010; Gioia et al., 2006; Krause et al., 2004; Tawashy et al., 2009). Indeed, differences in the psychological health domain scores were considerably higher in this study's population than all other quality of life domains.

Good quality of life measures may have reflected in positive self-esteem measures obtained by SCIPA Com participants. Although no experimental studies analysing LTPA and self-esteem were found for this population, a recent review observed a moderate association ($r = 0.23$ to 0.62) between self-esteem and improved quality of life (van Leeuwen et al., 2012a). Tzonichaki and Kleftras (2002) reported a moderate correlation between self-esteem with life satisfaction ($r = 0.43$, $P < .01$) and lower feelings of loneliness ($r = -.45$, $P < .01$) as well. SCIPA Com participants had significant increases in self-esteem measures (between 20.6; SD 5.7 and 22.1; SD 4.6), but much lower than those reported by a previous study (32.11; SD 4.62) developed by Coyle et al. (1994). They did not find significant differences in self-esteem scores between people with SCI and able-bodied individuals, though our participants consistently indicated lower scores in RSS items affected by their physical impairment (i.e. "I am able to do things as well as most other people", and "I certainly feel useless at times"). Investigations in larger populations are necessary to clarify differences between studies.

SCIPA Com's active group also reported significant functional, self-esteem, and quality of life improvements immediately after the physical activity program in the community setting. Differences in quality of life follow-up assessments of six and nine months remained the same, displaying ingrained positive health behaviours (Ingledew et al., 2004; Park & Peterson, 2009). Long-term adherence to physical activity was also better in the active group with more people above the physical activity threshold (100% at three months, 89% at six months, and 93% at nine months) compared to the inactive group (76% at three months, 47% at six months, and 50% at nine months). Similar studies did not report on adherence levels, though retention rates ranged between 67% and 70% (Froehlich-Grobe et al., 2014; Wise et al., 2009). Other researchers from the *SHAPE-SCI Research Team* from Canada

have obtained promising results via cognitive behavioural training and counselling sessions to promote self-regulatory skills, intentions, and action plans which may boost LTPA levels and adherence to community-based programs (Brawley et al., 2013; Latimer-Cheung et al., 2013).

4.9 CONCLUSIONS

The ecological validity of the SCIPA Com program was based on the introduction of community dwelling adults with SCI to exercise professionals new to adapted physical activity. This study demonstrated the effectiveness of structured physical activity programs under the supervision of qualified exercise professionals in community fitness centres. Not only did it increase physical activity participation among inactive individuals with SCI, but also reflected in significant quality of life, self-esteem, and functional improvements. Constant levels of physical activity were obtained among active individuals. Differences between groups were confirmed, possibly due to ceiling effects of LTPA among the active population, though they obtained additional improvements in social and functional satisfaction. Findings encourage the promotion of public health initiatives among active and especially inactive individuals with SCI living in the community.

Support from credible SCI networks and hospital staff throughout the recruitment process, as well as collaborations with community-based organisations underpinned positive results obtained by SCIPA Com. In other words, this research reinforces the need of cooperation between health, educational, and community services.

The following recommendations were extracted from experiences throughout the SCIPA Com program:

1. Rehabilitation professionals are advised to inform and mediate the process of community re-integration of individuals with SCI and guide exercise professionals on safe and efficient delivery of a physical activity programs in the community;
2. Tailored physical activity programs are endorsed to ensure realistic planning and client adherence, as well as structured ongoing support;

3. Training precautions need to be emphasised among inactive and active people with SCI, particularly concerning autonomic dysreflexia and biomechanical muscles imbalances of upper limbs among wheelchair users;
4. Exercise professionals require further training and support to lead public health initiatives in the community among populations with disabilities.

In the future, experienced exercise professionals may play a pivotal role in delivering improved outcomes for clients with SCI living in the community. Inactive individuals with SCI will be likely to benefit even more from enhanced supervision and resources on the promotion of positive health behaviours, such as those in the SCIPA Com. Further measures are warranted to assist individuals that did not adhere to physical activity (approximately 50% of the inactive group in the last follow-up period) in the later stages of assessments. Factors associated to inactivity, such as financial constraints, advanced age, gender role barriers faced by women, and lack of community engagement need to be considered and addressed with more emphasis in prospective studies.

4.10 ETHICS AND LIMITATIONS

The execution of a randomised controlled trial was not possible due to the necessity of matching individuals with SCI to exercise professionals from community fitness centres in proximity of their homes (impeding randomisation). As stated previously, this study did not employ a control group. A stepped-wedge design was initially considered for this study in order to form a control group. This control group would have had their intervention delayed for three months in order to enable comparisons with those that completed the SCIPA Com training. However, this design was soon found to be counterintuitive since participants were demotivated or lost interest during the waiting period and did not follow through with the intervention. Finding homogenous intervention and control groups is highly unlikely since each SCI is unique and participants present inherent differences. Therefore, the effects of the intervention could not be controlled for bias and a quasi-experimental design with pre- and post-measures was adopted to analyse outcomes.

Recruitment of exercise professionals presented challenges because this was done on a voluntary basis. As self-employed professionals, their time dedicated to the program was often considered a disadvantage without a source of income. Discounted personal training rates needed to be negotiated to defray loss of revenue. This also restricted the quantity and duration of sessions provided to clients with SCI. Participants may have not trained at a sufficiently high level for their potential considering that additional LTPA could have led to better results in both groups assessed.

Clients were also informed of the standard risks of physical activity participation, namely mild muscular soreness and mild fatigue before they signed the consent form to participate in SCIPA Com. Safety precautions were emphasised; nevertheless, one participant re-injured his shoulder due to excessive weight training. Though improved fitness and strength help injury prevention, shoulder injuries remain an issue and require further investigations to avoid such complication.

Time constraints related to the thesis enrolment deadline limited data collection in the final follow-up period. This resulted in a smaller sample (n=40 at the nine months mark) compared to the previous follow-up period (n=61 at the six months mark). Though response rate was 100% out of the 40 individuals last assessed, 21 individuals were not contacted, which may have reduced the statistical power of results and may have reflected a bias location-wise as the early recruitments were in Australia.

Chapter 5: Analysis of Positive Personality Attributes in Clients as Predictors of LTPA

STUDY 3

This study is the first attempt to analyse personality attributes that may be associated with LTPA among individuals with SCI. *Study 3* is described in the following sections:

Section 5.1 Introduction on Positive Psychology and personality attributes considered important for physical activity behaviour in the SCI population.

Section 5.2 Methods and research design adopted in *Study 3*.

Section 5.3 Participants involved in this study, namely exercise professionals and clients with SCI.

Section 5.4 Procedures conducted in the identification and development of positive personality attributes scales

Section 5.5 Positive Personality Attributes Scales

Section 5.6 Statistical analysis performed.

Section 5.7 Results collected from the Positive Personality Attributes Scales

Section 5.8 Discussion concerning findings and associated literature.

Section 5.9 Conclusions from this study, and

Section 5.10 Ethics and limitations of *Study 3*.

5.1 INTRODUCTION AND BACKGROUND

In general clinical practice, physical activity promotion strategies in the community have not yielded high levels of participation or substantial long-term improvements (Elley et al., 2007; Kahn et al., 2002). This ineffectiveness represents a great concern for the SCI population, who are highly susceptible to sedentarism (Martin Ginis et al., 2010e). Physical activity is essential for this cohort in maintaining well-being and preventing serious secondary health issues that may follow, such as cardiovascular and metabolic diseases (Cowan & Nash, 2010; Cragg et al., 2013c; Jacobs & Nash, 2004; van Leeuwen et al., 2012a; van Leeuwen et al., 2012f).

Researchers have identified factors that underpin physical activity behaviour, such as physical (i.e. pain, fatigue, and function), psychological, social, behavioural, environmental, and policy correlates as determinants (Kahn et al., 2002; Martin Ginis et al., 2012a; Tawashy et al., 2009). For example, more time spent in rehabilitation and less severe clinical presentations of SCI (Teeter et al., 2012); improved accessibility to facilities and social integration of people with SCI (Cowan et al., 2013; Kehn & Kroll, 2009; Vissers et al., 2008) are known to influence LTPA engagement. However, length of stay in Australian hospitals is progressively reducing and severity of a chronic SCI is generally a non-modifiable characteristic. These clinical findings are fundamental for the facilitation of physical activity; they do not provide information on behavioural or social mechanisms associated to training. In fact, there is an evident lack of literature that provides a basis for testable predictions on future physical activity behaviour or holistic intervention choices and strategies (Dunn & Elliott, 2008).

Researchers in the behavioural field consider human nature to be extremely adaptable and a product of natural selection and human evolution (McAdams & Pals, 2006); thus, several studies have targeted behavioural changes to induce increased physical activity (Brawley et al., 2013; Latimer-Cheung et al., 2013; Latimer & Martin Ginis, 2005). An extensive North American study analysing 235 sedentary adults found that behaviourally-based lifestyle interventions (i.e. teaching the general population modifiable behavioural skills) to be more cost effective than structured exercise programs to increase moderate-intensity physical activity engagement among the general population (Sevick et al., 2000).

Information available on predictors of physical activity behaviour in the SCI population recognised the importance of self-regulation (Martin Ginis et al., 2011m), self-efficacy (Kroll et al., 2007a; Martin Ginis et al., 2013; Phang, Martin Ginis, Routhier, & Lemay, 2012), and personality attributes (e.g. being optimistic, attentive, dedicated, and receptive to feedback) (Teeter et al., 2012). The focus of this research has been mainly driven to the study of perceived self-efficacy, i.e. “beliefs on one’s capabilities to organise and execute the courses of action required to produce given attainments” (Bandura, 1997), due to its positive role in sustaining a physically active life style (Arbour-Nicitopoulos et al., 2009; Kroll et al., 2007a; Kroll et al., 2012; Nooijen et al., 2013; Phang et al., 2012). Self-regulatory self-efficacy, facilitated via action and coping plans (i.e. establishing and performing LTPA sessions with determined frequency, duration, and intensity, as well as planning on how to overcome barriers), is also valued for supporting people in the pursuit of their goals (Latimer-Cheung et al., 2013; Schwarzer et al., 2011). Nonetheless, little attention has been drawn to the larger spectrum of personality attributes and their influence in physical activity behaviour of individuals with SCI.

Personality is conceived as a product of:

“(a) an individual’s unique variation on the general evolutionary design for human nature, expressed as a developing pattern, (b) dispositional traits, (c) characteristic adaptations, and (d) self-defining life narratives, complexly and differentially situate, (e) in culture and social context.” (McAdams & Pals, 2006)(p. 204).

Personality *traits* pertain to how someone typically behaves across various situations and contexts. Conversely, human behaviour is typically situation-specific and not predictable overtime. Whereas *traits* are relatively consistent, characteristic adaptations (i.e. personality *attributes*) are human particularities that address contextual changes (McAdams & Pals, 2006). They concern motivational (e.g. *I exercise because it is fun and beneficial*), social-cognitive (e.g. *does my partner think it is important for me to exercise on a regular basis*), and developmental skills (i.e. *progressive acquisition of knowledge and abilities overtime*). Life narrative is a broader concept which implicates the evolution of traits and attributes according to one’s sense of purpose and modern society’s requirements; that is, identities developed through the integration of the past, current, and futures selves. Culture is a strong combination of beliefs and practices that have an additional profound impact on characteristic adaptations and life narratives (McAdams & Pals, 2006).

Unlike personality *traits* (e.g. extraversion, conscientiousness, and neuroticism) (Ingledew et al., 2004; McAdams & Pals, 2006; Park & Peterson, 2009), personality *attributes* such as motivation, self-efficacy, and self-determination are more susceptible to changes through interventions that enhance LTPA (Bauman et al., 2012; Brawley et al., 2013; Nooijen et al., 2013; Ryan & Deci, 2000; Ryan et al., 2008). Positive personality attributes are part of the psychological resources family, a valuable set of abilities, knowledge, and behavioural patterns that can be fostered to achieve effective health outcomes (Peter et al., 2012). Further information on personality attributes considered important to increase physical activity levels in people with SCI could direct future interventions through motivation and self-efficacy strategies, leading to better outcomes (Deci & Ryan, 2000; Ryan & Deci, 2000).

Positive Psychology scholars have taken important steps towards the analysis of attributes, traits, experiences and surroundings that largely impact quality of life in the general population (Park & Peterson, 2009; Seligman & Csikszentmihalyi, 2000). The foundations of Positive Psychology lie on the understanding and promotion of human strengths to enhance psychological and physical well-being rather than attending primarily to pathologies (Buntinx, 2013). The *Values in Action Inventory of Strengths* (VIA-IS), developed by Park and Peterson (2009), has been extensively used to capture an individual's personality strength profile. Their findings had important implications for educators, parents, mental health professionals, and policy makers. For example, academic achievement among middle-school and college students was predicted by the character strengths of perseverance, love, gratitude, hope, and perspective; the effectiveness of teachers was judged on their social intelligence, zest, and humour; and people considered brave and with appreciation of beauty demonstrated improved recovery from illnesses. Thus, the encouragement of character strengths led to improved knowledge, health, and social connections.

Within the disability context, positive attributes and strengths have not been adequately conceptualised; on the contrary, people with disabilities have been historically perceived as incapable, often experiencing discrimination and marginalisation (Buntinx, 2013; The United Nations, 1992). The *United Nations Convention on the Rights of Persons with Disabilities* was brought forth to the international community to represent the foundations and values required to develop an equitable society (The United Nations, 2006). The *Convention* supports social inclusion and participation, which in turn increases autonomy and perceived value of

health strategies (i.e. self-determination) (Buntinx, 2013). Thus, the assessment of positive personality and functional strengths has been on the rise in the field of ecological psychology, along with the development of support systems.

The current version of the American Association on Intellectual and Developmental Disabilities' (American Association on Intellectual and Developmental Disabilities & Schalock) conceptual framework of human functioning brought a positive outlook on disabilities. They further endorsed the integration of the individual's abilities and needs into the support systems level (American Association on Intellectual and Developmental Disabilities & Schalock, 2012). Information on personality attributes could help direct the focus of interventions and even predict the rehabilitation progress by analysing those associated with physical activity behaviour (Park & Peterson, 2009). An important form of support system that would also benefit from knowledge in personality attributes is the strengths-based support strategy (Buntinx, 2013). This system is focused on empowering people with disabilities through the identification and development of a person's abilities and attributes before resorting to means that increase dependency (Buntinx, 2013). In the community setting, exercise professionals could integrate Positive Psychology principles into their clients' physical activity program and identify strengths that favour of increased health outcomes (Elley et al., 2007; Sevick et al., 2000).

Among individuals with SCI, the conceptualisation of positive personality attributes and their promotion could be used to strengthen signature qualities and reverse inactivity (Park & Peterson, 2009; Rohe & Krause, 1999). Positive practices have the potential of encouraging health professionals to involve and facilitate their client's skills and support network instead of imposing their professional skills for a restricted amount of time. Such client-centred approaches are effective in finding each individual's strengths and tailoring strategies according to them, without simultaneously undermining the pathology, impairments, limitations, and barriers (Claes et al., 2010). This approach could also lead to a better understanding of intrapersonal attributes and how they interact with their surroundings (Dunn et al., 2013).

Support strategies for people with disabilities have proposed the integration of client goals and resources with activities that involve education, assistance, treatment, or training (Buntinx, 2013). Interventions based on psychological theories of planned (Ajzen, 1991; Latimer & Martin Ginis, 2005) and social-cognitive behaviour (Bandura, 1997; Brawley et al., 2013; Martin Ginis et al., 2011m), as well as the *Health Action Process Approach* (HAPA) (Martin Ginis et al., 2013;

Schwarzer, 2008) have helped address issues and significantly increased LTPA levels among people with SCI. Positive cognitive and behavioural strategies (e.g. creating routines, setting goals, perceiving exercise mastery, and accepting assistance) (Kerstin et al., 2006; Lannem, Sørensen, Lidal, & Hjeltnes, 2010); the exploration of sources of motivation (e.g. independence, improved health and physical appearance, enjoyment, and socialisation); and adaptation to their condition also provided encouraging results (Arbour-Nicitopoulos et al., 2009; Kehn & Kroll, 2009; Kerstin et al., 2006; Martin Ginis et al., 2012a; Martin Ginis et al., 2013). These findings coupled with Positive Psychology principals could enhance and integrate constructive behaviour and strengths.

Little information on personality attributes in the SCI population or if they predict LTPA behaviour is currently available. Like-wise, information regarding personality attributes clients expect from their exercise professionals is non-existent. No specific instrument was found to evaluate personality attributes in individuals with SCI and people they interact with. Assessment tools such as the *VIA-IS*, *Leisure Motivation Scale*, AAIDD's assessment framework are not specific to the SCI population or theme in case, aside from being time consuming or unavailable in English (McGrath, 2014; Park & Peterson, 2009; Pelletier, Vallerand, Green-Demers, Blais, & Brière, 1996; Schalock & Verdugo, 2012). Therefore, positive personality attributes must be identified and scales need to be developed to measure relevant attributes. The information obtained may reveal attributes that underpin increased LTPA in individuals with SCI.

In order to identify attributes that enhance LTPA and are endorsed by the SCI population, an initial exploratory analysis is necessary. Once positive personality attributes related to physical activity participation are identified, they can be analysed and converted into scales. These scales can be used to assess themselves (i.e. individuals with SCI) and other health professionals involved in their structured physical activity program.

In this study, health providers are represented by exercise professionals. They should consider and encourage their clients' personality attributes, physical capacity, and goals to increase the effectiveness of their intervention (Teeter et al., 2012). Exercise professionals must also be assessed regarding attributes they consider important to enhance LTPA among themselves and clients with SCI for improved interpersonal understanding.

Thus, this study was divided into two stages: *Stage 1* involved:

- a) the examination of positive personality attributes deemed relevant among clients with SCI and exercise professionals to encourage LTPA participation in the SCI population;
- b) development of positive personality attributes measures for clients with SCI and exercise professionals; and
- c) measures of baseline LTPA levels as a pre-intervention reference of physical activity behaviour.

Subsequently, clients with SCI and their respective exercise professionals conducted a structured physical activity program based on the client's personality attributes, physical capacity, and goals for the duration of eight-to-twelve weeks (refer to **Chapter 4: Study 2, Spinal Cord Injury and Physical Activity in the Community program**).

Stage 2 took place following the end of SCIPA Com and consisted of:

- d) the examination of whether positive personality attributes reported on scales predict LTPA behaviour after intervention.

5.1.1 Research questions

The main research questions prompted by insufficient evidence in literature were:

- From the perspective of people with SCI, which positive personality attributes are considered important for the enhancement of LTPA levels among individuals with SCI?
- From the perspective of exercise professionals, which positive personality attributes are considered important for the enhancement of LTPA levels among individuals with SCI?
- In a SCI/exercise professional context, how do self- and other-perceptions of positive personality attributes correlate with LTPA levels after a structured physical activity program developed according to the clients' goals, personality and physical strengths?

5.1.2 Objectives

The objectives of *Study 3* were to:

- Identify positive personality attributes deemed relevant to clients with SCI and exercise professionals in order to enhance LTPA levels among individuals with SCI;
- Develop two positive personality attributes assessment instruments, one for clients with SCI and another for exercise professionals, to test their prediction capability regarding LTPA levels after a physical activity intervention program based on clients' goals, personality and physical strengths and overtime.

5.1.3 Hypotheses

The hypotheses elaborated were:

- That positive personality attributes (i.e. motivation, commitment, self-efficacy, etc.) assist the prediction of LTPA levels after a physical activity program based on their goals, personality attributes and physical strengths;
- That high levels of positive personality attributes perceived between clients with SCI and exercise professionals will display better LTPA outcomes than those with discordant assessments.

5.2 METHODOLOGY AND RESEARCH DESIGN

This study was based on an exploratory analysis for the identification of personality attributes in clients with SCI and exercise professionals in the LTPA context through the principles of Positive Psychology (O'Reilly & Parker, 2013; Seligman & Csikszentmihalyi, 2000). Subsequently, a correlational analysis between positive personality attributes and levels of LTPA was performed to identify the relationship between the aforementioned variables over three time periods: subsequent to an eight-to-twelve week physical activity program based on their goals, personality and physical strengths; and two times after with three months in between each assessment.

Stage 1 of this study involved a qualitative inductive approach to reveal further information on positive personality attributes between the cohorts analysed (O'Reilly & Parker, 2013). Codes extracted from individual interviews were subjected to thematic analysis and compiled for the development of positive personality attributes scales. These scales were used in the second phase (*Stage 2*) for a quantitative assessment of continuous variables, namely the variation of LTPA levels (dependent variable) over three separate time periods in relation to positive personality attributes (independent variable).

5.3 PARTICIPANTS

The target cohorts of *Study 3* were individuals with SCI and their respective exercise professionals that took part in SCIPA Com. The inclusion criteria were the same used for *Study 2* (**Chapter 4**, under **4.3 Participants**), with the addition of providing informed consent to participate in this portion of the study.

5.4 PROCEDURES

Participants were initially informed of the confidential and voluntary nature of this study, and reminded of their freedom to withdraw from the process at any time. All respondents were fully debriefed on the procedures and given the opportunity to elucidate their doubts before consenting to their participation. This study received the approval of the Human Research Ethics Committee of Curtin University (PT0190/2011).

In *Stage 1* of *Study 3* (*Stage 1*, i.e. before SCIPA Com) the first 15 participants included in the program participated in a one-on-one interview. A short semi-structured interview was performed to identify positive personality attributes deemed important for physical activity participation and develop positive personal attribute scales to examine how they influence LTPA. Participants were asked to describe and list the individual characteristics (i.e. personality attributes) required from clients with SCI and exercise professionals in order to increase activity and participation of individuals with SCI living in the community (via community fitness centres).

Once positive personality attributes were identified, they were analysed and coded. Recurring attributes provided the basis for the generation of scales specifically for this study regarding self-assessment and other-assessment between participants. Three independent experts were asked to rate the relevance of each item using a 5-point scale anchored at -2 (very poor) and 2 (very good) to select which items should be included in the measuring instrument. Two scales, one for clients with SCI and another for exercise professionals, were generated and tested for internal reliability. Clients with SCI were further examined to determine baseline LTPA levels measured through the PARA-SCI tool (Latimer et al., 2006j).

The second phase of this study (i.e. Stage 2) followed the completion of the eight-to-twelve week physical activity program (SCIPA Com). Clients with SCI were once again measured for LTPA levels via PARA-SCI. Additionally, they read and answered the first portion of the Positive Personality Attributes Scales for Clients with SCI as they perceive themselves, and exercise professionals responded according to their thoughts towards their respective client. Like-wise, exercise professionals performed a self-assessment and clients with SCI completed other-assessments, though these responses were excluded because the number of parameters would exceed the sample size, thereby leading to non-identification of the model. An examination of the bivariate correlations indicated that there was little correlation between these other measures and physical activity. Finally, descriptive statistics and correlations were computed. The aim was to examine whether positive personality attributes reported on scales predicted LTPA behaviour immediately after the training program (three months) and over time. Thus, we chose to test clients with SCI at two other times for LTPA levels, namely six and nine months after the three months assessments.

5.5 MEASURES

To begin with, the qualitative component was based on two interview questions, one for each prospective participant of both cohorts:

Question directed to clients with SCI:

- What are the individual characteristics (i.e. positive personality attributes) of people with SCI you consider important to be physically active?

Question aimed at exercise professionals:

- What are the individual characteristics (i.e. positive personality attributes) of people with SCI you consider important for them to be physically active?

Answers to the questions above provided the information for the development of two Positive Personality Attributes in Physical Activity Participation Scales displayed in **Figures 5.1** and **5.2**.

5.5.1 Positive Personality Attributes in Physical Activity Participation Scale for Clients with Spinal Cord Injury

The Positive Personality Attributes in Physical Activity Participation Scale for Clients with Spinal Cord Injury included a self-assessment scale designed to examine the degree to which clients with SCI identify themselves with certain personality attributes in the physical activity context:

- *Self-assessment*: “When it comes to physical activity training, I am...”. Respondents were asked to rate on a 5-point scale (1 = *strongly disagree* to 5 = *strongly agree*) their perception in the attributes listed.

The scale comprised 10 self-assessment items resulting in a maximum amount of 50 points. The higher the score, the better one perceives their personality attributes

5.5.2 Positive Personality Attributes in Physical Activity Participation Scale for Exercise Professionals

The corresponding exercise professional scale, namely Positive Personality Attributes in Physical Activity Participation Scale for Exercise Professionals, paralleled similar constructs to evaluate clients with SCI:

- *Other-assessment*: “My client with SCI is . . .”. A second scale was developed to examine the opinion of exercise professionals on their client’s personality attributes that encourage them to participate in LTPA. Their perceptions were rated on a 5-point scale as well.

The self-assessment scale involved 9 items, resulting in a maximum amount of 45 points. Higher scores represent better self-perceived and other-perceived personality attributes.

Positive Personality Attributes in Physical Activity Participation Scale for Clients with Spinal Cord Injury

This scale is a series of positive personality attributes you perceive in yourself that encourage people with spinal cord injury (SCI) to participate in leisure time physical activity (i.e. physical activities done during free time, such as wheeling, playing sports, or exercising at a gym, not including daily activities that involve manual wheelchair use for mobility or work).

Each item represents a positive personality attribute considered important by **people with SCI**. Read each statement and decide to what extent it describes you.

Please indicate your personal answer by marking the box next to the statement that best describes you.

When it comes physical activity participation, I am:	Disagree Strongly	Disagree Moderately	Neither Agree nor Disagree	Agree Moderately	Agree Strongly
1. Motivated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Confident	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Committed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Flexible/Willing to try different exercises	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Realistic about my skills and potential	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Skilful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Competitive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Knowledgeable on how to exercise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Knowledgeable on the benefits of physical activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Figure 5.1. Positive Personality Attributes in Physical Activity Participation Scale for Clients with Spinal Cord Injury. Scale based on interviews conducted with people with spinal cord injury.

Positive Personality Attributes in Physical Activity Participation Scale for Clients as Assessed by Exercise Professionals

This scale is a series of positive personality attributes you perceive in your client with spinal cord injury (SCI) that encourage them (i.e. client with SCI) to participate in leisure time physical activity (i.e. physical activities done during free time, such as wheeling, playing sports, or exercising at a gym, not including daily activities that involve manual wheelchair use for mobility or work).

Each item represents a positive personality attribute considered important by **exercise professionals**. Read each statement and decide to what extent it describes your client with SCI.

Please indicate your personal answer by marking the box next to the statement that best describes your client with spinal cord injury.

My client with spinal cord injury is	Disagree Strongly	Disagree Moderately	Neither Agree nor Disagree	Agree Moderately	Agree Strongly
1. Motivated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Flexible/willing to try different exercises	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Courageous	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Optimistic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Respectful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Committed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Interested	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Friendly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Communicative	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Figure 5.2. Positive Personality Attributes in Physical Activity Participation Scale for Exercise Professionals. Scale based on interviews conducted with exercise professionals.

LTPA levels recorded for the same clients were used in the correlational analysis with positive personality attributes. These measures were obtained via the PARA-SCI (refer to **Chapter 4**, sub-heading **4.6. Measures, 4.6.2. Physical Activity Levels**).

5.6 QUALITATIVE AND STATISTICAL ANALYSIS

In order to analyse and code qualitative research findings obtained via individual interviews with clients with SCI and exercise professionals, answers were transcribed and transferred to QSR NVivo 10 (QSR International Pty Ltd, 2013). Following recommendations on reporting qualitative research findings (Sandelowski & Leeman, 2012), transcripts were systematically reviewed to uncover common positive personality attributes reported by multiple participants in both cohorts considered important for LTPA participation among people with SCI. ‘Saturation’ was attained when data collected stopped generating new information and an in-depth answer was provided to address the research questions (O’Reilly & Parker, 2013). Attributes were coded and organised through thematic synthesis, providing an interpretation and meaning to codes. Results were presented in tables comprising a list of personality attributes and their descriptions for ease of transferability and generalisation. These themes were reviewed and reflected upon their meaningfulness for research practice. Subsequently, items recorded on tables were used for the generation of positive personality attributes scales.

Quantitative data attained from Positive Personality Attributes Scales were screened for data entry errors. Clients’ self-reports and exercise professionals’ reports of the client on positive personality attributes were created using the mean response of the corresponding measured scale items. Demographic variables known to have an influence on physical activity levels, such as gender, age, and years since SCI (Bauman et al., 2012; Kroll et al., 2012) were included in the analysis to detect their correlation to baseline physical activity measures.

The model developed to guide the analysis of variables involved in this study is displayed on **Figure 5.3**. Self-perceived positive personality attributes referred to the perception of clients with SCI and other-perceived positive personality attributes expressed the opinions of exercise professionals; other variables involved in the

model (i.e. LTPA levels in four different time periods and demographic variables) pertained to measures in the SCI cohort.

Descriptive statistics of clients with SCI were computed using STATA/IC 13.1 for Windows (StataCorp LP, College Station TX, USA, 2013). The model depicted in **Figure 5.3** was tested using path analysis in Mplus (Muthén & Muthén, 2012). A maximum likelihood estimator with robust standard errors (MLR), which is appropriate for use with response scales that comprise five or more categories, was employed to account for the biasing effects of non-normality (Bandalos, 2014; Rhemtulla, Brosseau-Liard, & Savalei, 2012).

A range of indices were employed to assess model-data fit, namely the χ^2 goodness-of-fit index, comparative fit index (CFI), Tucker-Lewis index (TLI), standardised root mean square residual (SRMR), and root mean square error of approximation (RMSEA). Acceptable model-data fit is provided by a non-significant χ^2 goodness-of-fit index; when this value is significant, model fit is considered acceptable with CFI and TLI values > 0.95 , alongside SRMR and RMSEA values < 0.05 (Byrne, 2012; Hu & Bentler, 1999).

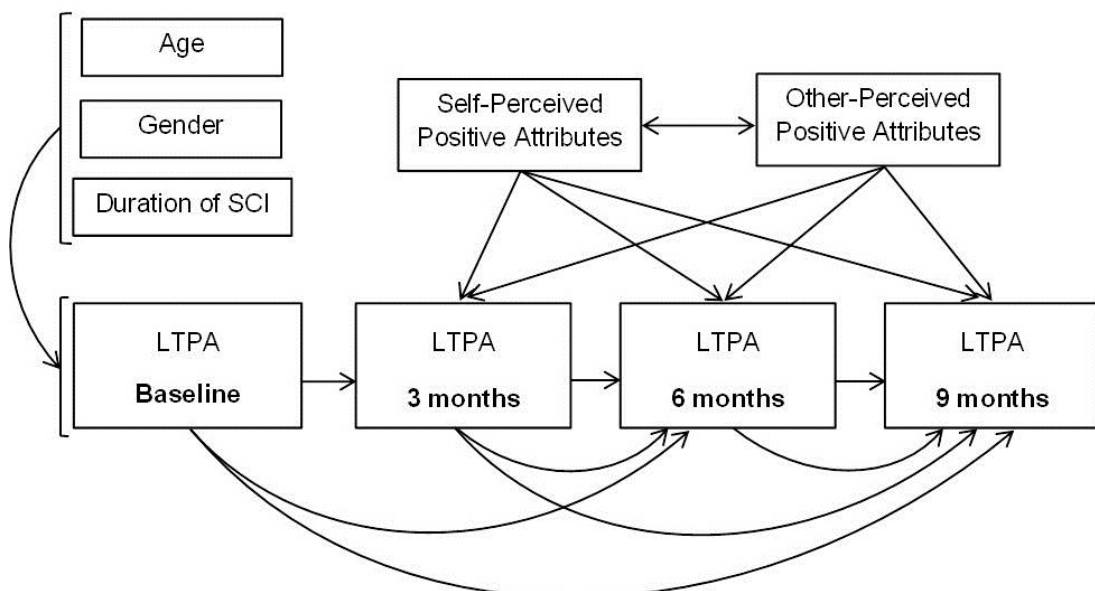


Figure 5.3. Positive Personality Attributes Model, involving self-perceived positive personality attributes and other-perceived positive personality attributes of clients with SCI; LTPA levels in four different time periods and demographic variables from the SCI cohort.

5.7 RESULTS

The first 15 clients with SCI and the equivalent amount of exercise professionals from the SCIPA Com program took part in *Stage 1*, the interview section. *Stage 2* followed the eight-to-twelve week physical activity program, when 58 pairs of clients with SCI and exercise professionals answered the Positive Personality Attributes Scales. Demographic characteristics of participants in *Stage 1 and 2* are presented on **Table 5.1**. No significant differences were found for demographic characteristics between the initial sub-group in *Stage 1* (n = 15) and the final sample (N = 58) in *Stage 2*.

Table 5.1. Baseline demographic characteristics of clients with SCI in *Stages 1 and 2*.

	Stage 1 (n = 15)	Stage 2 (N=58)	P
Gender (%)			.209
Male	86.6 (13)	70.6 (41)	
Female	13.3 (2)	29.3 (17)	
Age (y)	53.2 ± 14	49.2 ± 13	.313
SCI Classification (%)			
Tetraplegia complete	20 (3)	17 (10)	.820
Tetraplegia incomplete	26.6 (4)	31 (18)	
Paraplegia complete	26.6 (4)	28 (16)	
Paraplegia incomplete	26.6 (4)	24 (14)	
Years since SCI (y)	15 (3-28)	9.5 (2-22)	.399
Physical activity levels (min)	30 (0-65)	10 (0-60)	.354

Note. Values expressed as %, mean ± SD, or median and interquartile range (IQR). Significant differences between cohorts in *Stage 1* and *Stage 2* were tested using independent t-test (continuous), Mann-Whitney U (continuous), and Chi square test (categorical). No significant differences were found between baseline demographic characteristics between participants in *Stage 1* compared to the total sample in *Stage 2* ($P > .05$).

5.7.1 Stage 1

The list and frequency of positive personality attributes that clients with SCI perceived as important for physical activity participation in themselves and their exercise professionals are listed on **Table 5.2**. Though satisfaction with their exercise professional and being comfortable in the environment did not figure as attributes, they were frequently reported by the cohort of the present study.

Table 5.2. Thematic synthesis and the frequency they were endorsed among clients with SCI regarding questions on personality attributes they need to present (self-assessments) and attributes exercise professionals require (other-assessment) to encourage physical activity participation in the SCI population (n = 15)

Which individual characteristics (i.e. personality attributes) do you consider important to enhance <i>physical activity and participation of individuals with SCI living in the community?</i>			
Self-assessments	N	Other-assessment	N
(Self) motivated; excited to participate in physical activity	10	Motivating and encouraging towards clients during activities	13
Committed to the physical activity program and/or to my exercise professional	9	Knowledgeable; having an understanding of spinal cord injury (SCI) and the effect it has on individuals with SCI	12
Confident in my own ability to exercise	7	Good communicator to convey proper instructions on techniques and benefits of physical activity	11
Goal-driven; having goals to achieve determined outcomes	7	Friendly; having good interpersonal skills to build a positive rapport with clients	9
Realistic about my skills and potential to exercise	5	Efficient; promoting improved physical and functional gains in clients with SCI	7
Competitive with myself and/or with others to achieve better outcomes	5	Flexible and adaptable with exercises in case clients are not able to perform activities in conventional ways	6
Skilful and physically capable of exercising	4	Understanding and respectful; who treats clients with SCI as anyone else	5
Flexible and willing to try different exercises	3	Helpful during preparation and execution activities with client with SCI	4
Patient in preparing gym equipment for use and learning new activities	3	Usually available to assist a client during activities	2
Knowledgeable on the benefits of physical activity	3	Being an example of fitness and health	3
Knowledgeable on how to exercise	2	Committed to the client and training regime	3
Positive; optimistic towards physical activity and outcomes	1	Experienced in physical activity and adapted training for clients with SCI	2

Note. The numbers represent the frequency clients mentioned the corresponding attributes.

In turn, exercise professionals expected to increase LTPA levels of their clients with SCI if both of them presented positive personality attributes listed on **Table 5.3**. Positive Personality Attributes Scales derived from items listed on both **Tables 5.2** and **5.3** (refer to sub-heading **5.6. Measures**).

Table 5.3. Thematic synthesis and the frequency they were endorsed among exercise professionals regarding questions on personality attributes they need to present (self-assessments) and attributes clients with SCI require (other-assessment) to encourage physical activity participation in the SCI population (n = 15).

Which individual characteristics (i.e. personality attributes) do you consider important to enhance <i>physical activity and participation of individuals with SCI living in the community?</i>			
Self-assessments	N	Other-assessment	N
Knowledgeable in physical activity and its effects on individuals with SCI	10	Motivated to engage in physical activity	13
Confident in my skills to train a person with SCI	9	Interested; willing to learn new exercises and activities	12
Respectful and tactful towards my client with SCI	9	Confident in my work and abilities	10
Encouraging; motivating; positive; energetic with my clients with SCI during training	9	Flexible; willing to try different exercises and activities	6
Friendly; approachable towards clients seeking assistance	8	Good communicator to express their goals and needs	6
Understanding; empathetic to difficulties presented by clients with SCI	7	Committed to the physical activity program	4
Dedicated to my client and physical activity program	3	Respectful towards exercise professional	3
Present and helpful for clients with SCI	3	A positive thinker and optimistic towards physical activity and outcomes	3
Flexible and adaptable to propose activities according to the clients characteristics	3	Friendly to build a positive rapport with their exercise professionals	3
A good listener and understand the clients' needs	3	Goal-oriented; having goals to achieve determined outcomes	2
Cautious during training to ensure client safety	3	Patient in obtaining gains from physical activity	1
Patient with clients and time necessary to adapt activities	2		

Note. The numbers (N) represent the frequency clients mentioned the corresponding attributes.

5.7.2 Stage 2

LTPA levels were measured four times in order to establish a reference baseline measure before undergoing the SCIPA Com program, and several months after receiving the intervention. Changes in LTPA levels were observed among 37 clients with SCI over the subsequent follow-up periods as shown on **Table 5.4**. Values are better expressed in median and interquartile range due to the non-parametric distribution in LTPA levels across individuals. Compared to baseline measures, LTPA levels increased significantly following intervention and at nine months assessments. Differences between LTPA at three months and six months revealed a significant decrease in LTPA levels. Differences between three and nine months (-10.2, 95%CI: -21.8 to 1.3; $P = .082$), as well as six and nine months (4.2, 95%CI: -7.7 to 16.2; $P = .485$) were not significant.

The hypothesised model provided an excellent fit with the data ($\chi^2 = 5.02$, $P = .54$, CFI = 1.00, TLI = 1.00, SRMR = .033, RMSEA .000, 95%CI: .000 to .154). Both self-perceived ($\alpha = .80$) and other-perceived positive personality attributes ($\alpha = .93$) were found to be internally reliable. Within the model, people who were of the female gender or/and sustained a SCI for several years presented, respectively reported lower levels of baseline and nine months LTPA. Physical activity behaviour at baseline significantly predicted LTPA levels immediately after intervention (.48, 95%CI: .31 to .64), six months (.32, 95%CI: .09 to .56), and nine months (.28, 95%CI: .03 to .54).

The average score obtained in the Self-Perceived Positive Personality Attributes Scale for Clients with SCI was 42.7 (SD ± 1.41) out of 50. High levels of self-perceived positive personality attributes in the SCI cohort were significant predictors of increased LTPA levels immediately following intervention (three months) and after six months. Interestingly, high levels of self-perceived positive personality attributes had an inverse effect on LTPA levels in the last follow-up period. Self-perceived positive personality attributes were not related to other-perceived positive personality attributes (-.19, 95%CI: -.43 to .05) and, though exercise professionals rated their clients highly with an average of 41.1 (SD ± 7.0) points out of 45, other-perceived positive personality attributes did not have a significant effect on LTPA levels at any moment assessed.

The intervention (i.e. eight-to-twelve week physical activity program based on the clients' personality strengths, physical capacity, and goals) was not a significant predictor of LTPA levels in the assessments that followed (.14, 95%CI: -.14 to .42 at

six months and .19, 95%CI: -.30 to .41 at nine months) (refer to **Table 5.5**). This indicates that participants did not sustain improvements in LTPA levels at six and nine months follow-up at the same level compared to the three months follow-up assessment. However, LTPA levels at all follow-ups remained higher compared to baseline values and LTPA levels at six months were significant predictors of the results at nine months (.52, 95%CI: .27 to .77). The aforementioned results in relation to the model proposed are displayed in **Figure 5.4**. Estimates for the model and their confidence intervals, as well as the variance explained in LTPA levels at each time point are presented on **Tables 5.6**.

Table 5.4. Moderate and heavy leisure time physical activity over time (N=37, values expressed in minutes per day).

Clients with SCI (N = 58)							
Baseline		3 months		6 months		9 months	
Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)
26.9 (35.3)	10 (0 - 60)	54.7 (37.1)**	49.1 (30 - 69.3)**	36.5 (35.2)	30 (0 - 60)	38.7 (35.7)*	30 (0 - 60)*

Note. Mean and standard deviation (SD) of leisure time physical activity (LTPA) in minutes (min); Interquartile Range Q1 to Q3 (IQR); and probability (*P*) values compared to baseline.

***P* < .001, **P* < .05

Table 5.5. Moderate and heavy leisure time physical activity during baseline period compared to follow-up periods (N=37, values expressed in minutes per day).

Clients with SCI (N = 58)							
LTPA (min/day)	Baseline	3 months		6 months		9 months	
	Mean LTPA (SD)	Difference (95%CI) (min)	<i>P</i>	Difference (95%CI) (min)	<i>P</i>	Difference (95%CI) (min)	<i>P</i>
	26.9 (35.3)	23.9 (11.5 to 36.3)	.001*	9.3 (-3.1 to 21.9)	.142	13.6 (.16 to 27.1)	.047*

Note. Mean and standard error (SE) of leisure time physical activity (LTPA) in minutes (min) at baseline; LTPA difference in minutes (min) compared to baseline; 95% confidence interval; and probability (*P*) values compared to baseline.

***P* < .001, , **P* < .05

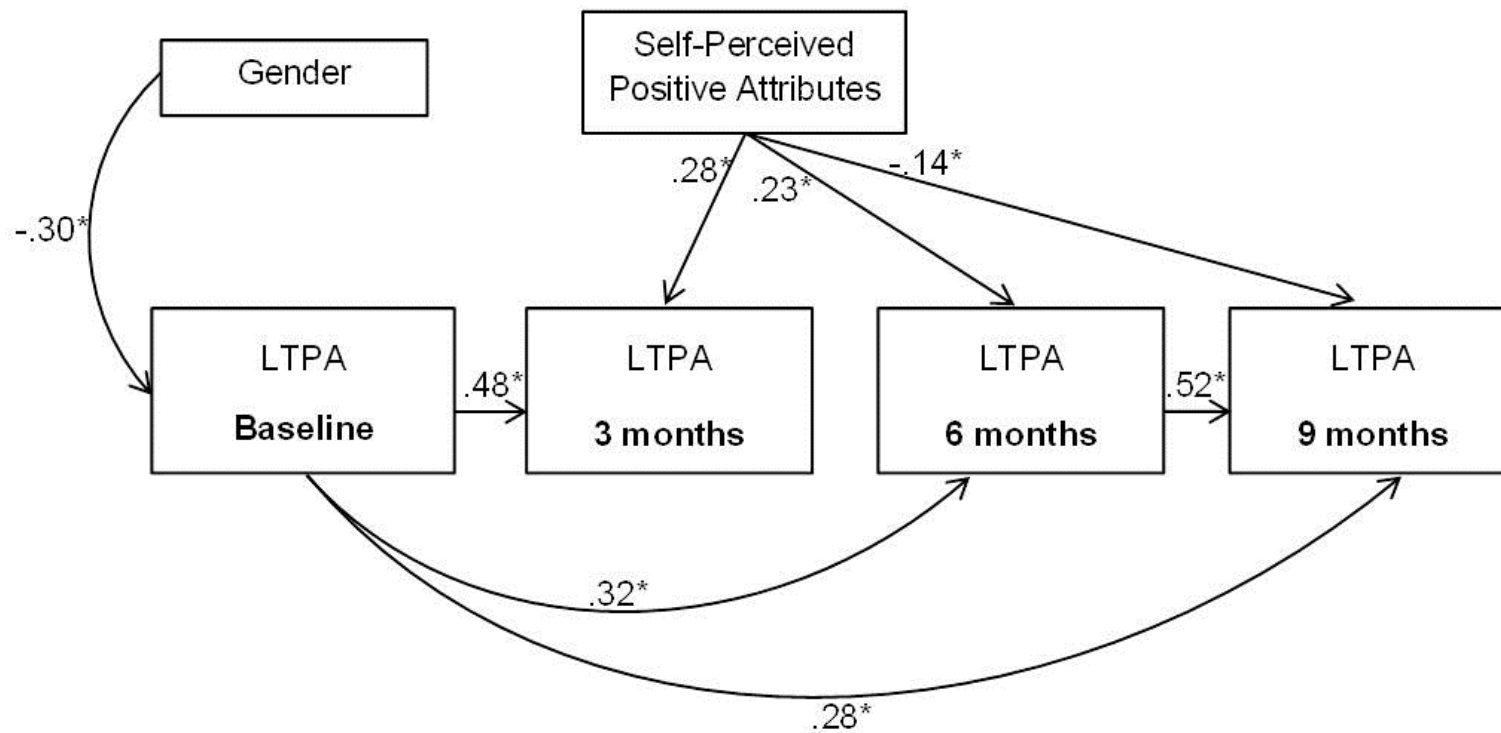


Figure 5.4. Direct effect coefficients for the model of Positive Personality Attributes as predictors of leisure time physical activity (LTPA). Note: $*P = .05$, $N=58$; non-significant paths are not presented in the figure.

Table 5.6. Estimates for the predictors within the Positive Personality Attributes Model and their 95% confidence intervals (CI), as well as the variance explained in leisure time physical activity (LTPA) over time.

Clients with SCI (N = 58)				
LTPA				
Predictors	Baseline (95%CI)	3 months (95%CI)	6 months (95%CI)	9 months (95%CI)
Gender	-.30 (-.44 to -.15)*	-.13 (-.29 to .04)	-.07 (-.33 to .20)	.12 (-.04 to .29)
Age	.04 (-.20 to .29)	.10 (-.08 to .29)	.11 (-.08 to .30)	.02 (-.13 to .18)
Duration of SCI	.11 (-.16 to .38)	-.11 (-.30 to .07)	.10 (-.15 to .35)	.001 (-.14 to -.014)*
Self-perceived personality attributes	-	.28 (.13 to .42)*	.23 (.05 to .40)*	-.14 (-.28 to -.01)*
Other-perceived personality attributes	-	.15 (-.01 to .32)	-.15 (-.35 to .04)	-.17 (-.38 to .05)

Note: * Statistically significant. When the confidence interval encompasses zero, results are considered non-significant.

5.8 DISCUSSION

This was an original study to test a Positive Personality Attributes Model as a predictor of LTPA among people with SCI. As projected in our first hypothesis, findings indicated that positive personality attributes are associated with LTPA behaviour among people with SCI in the community, especially after experiencing a physical activity program that accounted for their unique personality and physical attributes, as well as their goals. These attributes involved being motivated; committed to training and to their exercise professionals; having high levels of self-efficacy; valuing goals; being realistic about their condition and capabilities; having a sense of competitiveness; believing in their physical capacity; being open to alternative forms of physical activity; having patience during training, especially during the preparation time required before each activity; and being knowledgeable on how to exercise and its associated benefits. Thus, the first hypothesis was confirmed. Our second hypothesis was rejected: high-levels of positive personality attributes results between clients' and exercise professionals perspectives were not related to improved LTPA outcomes compared to those with discordant assessments.

Attributes identified have implications for the field of Positive Psychology, which is based on the enhancement of personality strengths and optimal functioning (Seligman & Csikszentmihalyi, 2000). Indeed, a previous study involving 1032 individuals with SCI confirmed that people considered motivated, optimistic, attentive to instructions, dedicated, and receptive to feedback were more likely to be participative in rehabilitation programs, leading to improved health outcomes (Teeter et al., 2012). Improved functioning, quality of life, social participation, mood and life satisfaction, as well as less rehospitalisation, and pressure sores followed those with enhanced positive personality attributes. In order to translate these benefits from rehabilitation settings into communities, the present study provided a 'snapshot' of positive personality attributes considered important for physical activity participation in fitness centres. No studies have adopted this approach before, though many have investigated the values and use of several personality attributes in isolation. Henceforth, the following discussion explores the findings of the present study, associated literature, and application of each attribute listed as described by previous authors.

Motivation was the overarching personality attribute responsible for positive physical activity behaviour among our clients with SCI. Though this study did not direct focus to the nuances of motivation, other researchers support the identification of the optimal type of motivation according to each individual's accumulated experiences and personalities (Carbonneau et al., 2012). This is based on the self-determination theory proposed by Deci and Ryan (1985) which states that leisure activities are regulated by autonomous and controlled forces, as well as lack of motivation. Internally regulated motivation (i.e. intrinsic motivation) is deemed to be the most effective form, though external regulation is where health professionals can intervene to modify one's motivation and self-determination.

A clearer understanding of a client's personality could reveal specific attributes that trigger motivation. Participants in SCIPA Com indicated goal-achievement, education on how to perform physical activity and perceived benefits as drivers, similar to observations described by Carbonneau et al. (2012) and Williams et al. (2014). In their studies, the learning aspect attracted curious individuals, interested in increasing their knowledge in determined areas. Achievement-oriented individuals found motivation via goals with higher standards. In the physical activity realm, Hein, Muur, and Koka (2004) observed that teenager's were more likely to be active by experiencing activities, and partially through accomplishments. Thus, researchers recommended challenging assignments and skills-oriented tasks to promote the sense of achievement for students motivated by accomplishments (Carbonneau et al., 2012). For those motivated by physical stimulation, sports and exercises proved to be more beneficial (Hein et al., 2004).

SCIPA com provided similar motivational prompts, which included goal setting and assisting the adaption of activities to the clients' abilities; learning new exercises; accomplishing eight-to-twelve weeks of training, and experiencing activities and social interactions. In fact, significant increases in LTPA in the three and nine months' follow-up periods indicated that motivation was positively influenced. This study provided clients with SCI the opportunity to assimilate and perform new activities and tasks, which may have increased the drive to learn. This is consistent with the proposed in previous research (Carbonneau et al., 2012; Park & Peterson, 2009). Motivation to accomplish tasks may have also been associated to other items listed, namely feeling committed and confident. As for experience stimulation, competitiveness and enjoyment are sensations often closely related to physical activity (Kehn & Kroll, 2009; Wu & Williams, 2001). Further stimulation in

SCIPA Com was provided through the utilisation of a new venue, i.e. fitness centres, especially for those initially inactive.

Interestingly, at the nine month period, high levels of self-perceived personality attributes were found to be negatively correlated to increased LTPA levels. Though we are not certain of what caused this inverse association, a decrease in self-perceived improvement may have occurred once participants achieved close to their maximum fitness levels and strength. Despite the effort and time dedicated to physical activity, individuals with SCI are often limited in physical capacity, presenting lower daily expenditure compared to able-bodied individuals, and are prone to secondary conditions such as cardiovascular diseases and neuropathic pain (Buchholz et al., 2003; Cowan & Nash, 2010; Cragg et al., 2013c; Finnerup, 2012; Gustin, Wrigley, Siddall, & Henderson, 2010; Jacobs & Nash, 2004). These events may be detrimental to ones' self-perception and motivation overtime. Once interventions ceased, so did the inputs and positive reinforcements provided by exercise professionals. The SCIPA program was a form of extrinsic motivation and when removed their PA declined, though it took 6 months for this to occur. Perhaps these individuals were motivated (i.e., high levels of LTPA), but the type of motivation was not commensurate with those forms required for sustained behaviour.

Along with motivation, confidence (i.e. exercise self-efficacy) was frequently cited among participants in SCIPA Com and is potentially the most widely studied personality attribute in SCI cohorts (Block et al., 2010; Kroll et al., 2007a; Kroll et al., 2012; Nooijen et al., 2013; Peels et al., 2014; Phang et al., 2012; Shields & Brawley, 2006). In the present study, self-efficacy was not studied separately from the other attributes identified. Further assessments are required to observe self-efficacy as its own entity and compare findings reported in literature. It is necessary to do so because, according to previous researchers, self-efficacy is a key modifiable belief in one's capabilities in attaining physical and functional improvements (Bauman et al., 2012; Nooijen et al., 2013). Self-efficacy has consistently been correlated with increased physical activity. In fact, an extensive review on correlates to physical activity in the general adult population identified self-efficacy and health status as the strongest correlates to physical activity (Bauman et al., 2012). Improved health status was further predicted through increased health self-efficacy ($P < .001$) following a chronic disease self-management intervention (Farrell, Wicks, & Martin, 2004).

Kroll et al. (2012) determined that self-efficacy explained between 3% and 8% of the variance of resistance and aerobic training in a sample of 612 adults with SCI from the United States of America. A community-based approach revealed superior self-efficacy and health related benefits in physical activity intervention groups compared to the control ($P = .007$) (Block et al., 2010), similar to the confidence presented by patients classified as exercisers ($P < .001$) (Kroll et al., 2007a; Nooijen et al., 2013), and those with better wheelchair skills (Phang et al., 2012). Their results revealed LTPA barrier self-efficacy (i.e. ability to overcome barriers in face of transportation, weather, pain and fatigue issues) as a significant partial mediator, explaining nearly 50% of the relationship between skills and LTPA (Phang et al., 2012). In turn, LTPA barrier self-efficacy increased motivation to engage in LTPA as individuals would be more likely to overlook barriers or form action and coping plans to reach fitness centres (Latimer et al., 2006a; Phang et al., 2012).

Researchers have used the term resilience to describe the intrapersonal quality of adjustment and capability amidst physical adversity (Dunn et al., 2013; Monden et al., 2014). SCIPA Com participants also found relevant having a realistic awareness of their capacity and perspectives. According to Arbour-Nicitopoulos et al. (2009) the sense of acceptance and pragmatism according to each ones skills and potential were related to adjustment or coping mechanisms incorporated by people with SCI into their daily lives. This ability has been identified in the field of psychology as a positive precursor, capable of enhancing assets (Dunn & Elliott, 2008; Dunn et al., 2013; Monden et al., 2014). Self-esteem and well-being are thereby leveraged, as well as motivation to accomplish a determined set of goals. Patience and willingness to experience different movements mechanisms are believed to result in neuroplasticity and further adjustment (Dunn et al., 2013).

When analysing a person's physical activity behaviour as a whole, numerous additional influences aside from personality attributes are involved. As observed in this study, concomitant factors such as previous engagement in physical activity (Bauman et al., 2012), gender (Bauman et al., 2012; Rauch et al., 2013), and years of SCI also significantly predicted physical activity behaviour in different assessment periods. As mentioned in **Chapters 3** and **4**, women are often found to be less active due to lack of support and generally being relegated to domestic activities, whereas men conform to physically demanding roles (Rauch et al., 2013). People who have sustained SCI for longer periods are also more likely to be precluded from physical activity as a consequence of secondary complications (i.e. overuse injuries and diminished physiological functions) (Fullerton et al., 2003; Nash, 2005; World

Health Organization, 2013). Though age was not a significant predictor in the present study, earlier reports infer an inverse correlation between age and physical activity levels (Bauman et al., 2012; Brown, Gordon, Spielman, & Haddad, 2002; Martin Ginis et al., 2012a; Warner, Basiletti, & Hoenig, 2010).

Further important physical activity predictors reported in literature include injury severity and how individuals perceive it. It is important to understand self-perceptions and attitudes amidst barriers, as they can be more incapacitating than a person's disability itself (Dunn et al., 2013; Whiteneck et al., 2004). For instance, the SCI population were previously found to either choose to avoid LTPA due to depression or to prevent pain, whereas others associated it to prevention or management of the same issues (Martin Ginis et al., 2012a; Martin Ginis et al., 2003). Our results suggest that a positive perspective towards personality attributes and possibilities could be pivotal in empowering people with SCI and stimulating adequate levels of physical activity participation, while opposing to behaviours that inhibit a healthy lifestyle.

Socio-environmental factors also play an important role in physical activity participation (Cowan et al., 2013; Jaarsma et al., 2014; Kehn & Kroll, 2009; Rimmer et al., 2004). Though not figuring as a personality attribute, satisfaction with their exercise professional and feeling comfortable in the environment were frequently reported by the cohort of the present study, reflecting an association between greater social integration with increased physical activity levels (Gainforth et al., 2014; Martin Ginis et al., 2012a). Integration in society has been positively associated with leisure activities, health, functioning, quality of life, education and work in the SCI population (Carpenter, Forwell, Jongbloed, & Backman, 2007; Müller et al., 2012). Participation in physical activity has also shown to influence social perceptions towards people with SCI. A study involving 446 able-bodied active people from Canada reported impressions in 17 personality and 9 physical domains of individuals with SCI either classified as exerciser, non-exerciser, and control (Arbour, Latimer, Martin Ginis, & Jung, 2007). Greater positive impressions were obtained towards active individuals with SCI compared to the other two classifications.

As for exercise professionals, the majority rated their clients highly across most personality attributes included in the scales. Positive interactions have shown to be beneficial, such as cases where athletes who received autonomy support from their coaches improved their self-determination towards their sport (Gillet, Vallerand, Amoura, & Baldes, 2010). Conversely, positive perceptions reported by exercise

professionals in this study did not present a strong association with LTPA in clients with SCI. Other studies were also unsuccessful in finding a link between supervision and motivation during leisure activities (Carbonneau et al., 2012; Wise et al., 2009). Indeed, the self-determination theory opposes to certain external prompts, such as rewards that diminish important constructs of motivation (i.e. autonomy, competence, and relatedness) (Deci & Ryan, 2000). Researchers believe that one's psychological needs for making decisions for themselves, have functional independence, and nurture proximity with others are the genuine motivational forces in the physical activity context (Gillet et al., 2010; Kawanishi & Greguol, 2013).

Another reason for discordant other-assessments and physical activity behaviour can be attributed to the exercise professional's *outsider* knowledge on life with a physical disability (Dunn et al., 2013). Society tends to focus on limitations and rarely challenges the abilities of a person with SCI, which demonstrates limited understanding of their context and the extent to which it impacts each person's existence. Moreover, misconceived stigmas attached to people SCI may have distorted the image exercise professionals have of people with SCI, often described as incapable and dependent (World Health Organization, 2013). Exercise professionals in this study were invariably a novice in training people with SCI and acquired knowledge and experience as SCIPA Com progressed. Individuals with SCI have, in general, better awareness of their needs; therefore, exercise professionals need to consider their clients' thoughts and opinions whilst working together (Kehn & Kroll, 2009).

Although perceptions from exercise professionals did not predict physical activity levels over time, variance in LTPA levels obtained imply their influence over increased physical activity levels among clients. Exercise professionals customised LTPA programs, addressed barriers and motivated clients, as recommended by previous research (Elley et al., 2007; Latimer et al., 2010; Rhodes et al., 2004). Significant improvements in physical activity levels maintained at nine months relative to the baseline levels possibly reflect the integration and consolidation of knowledge, skills, and self-determination, as posited by Ryan and Deci (2000).

According to their self-determination theory, external regulation can lead to integrated regulation, i.e., when individuals engage in activities because they realise their value and perceive them as goals. Scientists highlight the value of autonomy support in fostering positive self-determined actions (Ryan & Deci, 2000). This information is relevant to this study and advises exercise professionals on the importance of verbal reinforcements regarding benefits of physical activity,

determining the purpose of each task, identifying their clients' competencies, as well supporting their autonomy. Ryan et al.'s (2008) theory can be extrapolated to suggesting that professionals who consider and integrate their client's characteristics and opinions into their training programs are likely to promote self-determined forms of motivation and improved performance.

5.9 CONCLUSIONS

This was the first study to focus on positive personality attributes in relation to physical activity participation among individuals with SCI involved in a structured physical activity program. Important modifiable features identified in this cohort included motivation, confidence, commitment, adaptability, realistic expectations, patience, competitiveness, knowledge on how to exercise and associated benefits. These findings led to the development of the Positive Personality Attributes Scales in Clients with SCI and another from the perspective of exercise professionals (i.e. the Positive Personality Attributes Scales for Exercise Professionals). In this study, great significance was addressed to self-perceived attributes and important steps were taken towards the identification of key personality attributes associated to physical activity participation. Changes in the behavioural level were consolidated through customised physical activity programs.

The eight-to-twelve weeks customised intervention was effective in increasing LTPA levels for the whole cohort in the immediate (three months) and nine months follow-up assessments. Self-perceived positive personality attributes in clients with SCI predicted increased LTPA levels following intervention at three (.28) and nine months (.22) evaluations, though high levels of self-perceived personality attributes were negatively correlated to LTPA levels in the last follow-up period. This inverse association between self-perceived attributes at nine months might be related to the deceleration of health benefits perceived after an extended period of training, when one achieves close to their maximum fitness and power output. An alternative explanation is based on the absence of input and reinforcement of strengths provided by exercise professionals after the intervention period, or insufficient understanding of the reality of a sustaining a SCI.

Though the evaluation model did not indicate an association between how exercise professionals perceive their clients with their physical activity behaviour,

literature on self-determination theory endorses the constructive role of external assistance. Supporting literature also recommends the involvement of exercise professionals and the promotion of public health initiatives in community fitness centres (Elley et al., 2007; Froehlich-Grobe et al., 2014). Perhaps conducting assessments anonymously could provide more accuracy and different results. Further research is needed to analyse the inter-relationship between clients with SCI and exercise professionals and determine which personality attributes of the latter are implicated in enhancing physical activity among clients with SCI. Understanding how interest, accomplishments, and experiences are stimulated in clients with SCI could lead to higher levels of motivation and improved physical activity behaviour. Public health initiatives may benefit from the integral involvement of clients in the programs' development and decisions, as well as include measures that enhance positive personality attributes. These need to be nurtured and developed to improve exercise professional-client rapport and promote positive health habits.

5.10 ETHICS AND LIMITATIONS

Only the first steps for the development of Positive Personality Attributes Scales were performed. Further construct validity, intra- and inter-rater reliability studies need to be conducted to ensure the effectiveness of these scales. Data collected on positive personality attributes was limited to one point in time. Future research should study each personality attribute separately using longitudinal and prospective designs in order to investigate, for example, whether changes in attributes would lead to changes in certain outcomes (e.g. affect).

The sample included in this study mainly consisted of motivated individuals willing to participate in an eight-to-twelve week physical activity program, which may have excluded the expectations of unmotivated individuals. A multi-sampling test of the model could increase the generalizability of our findings. The Positive Personality Attributes Scale for Exercise Professionals and exercise-professional other-assessment lacked sensitivity, possibly due to the high levels of self and other-perceived scores collected between the participating cohorts or misconceived beliefs. Future studies are still required to clarify the underlying mechanisms of successful inter-relationships between exercise professionals and clients with SCI in promoting high levels of physical activity.

Chapter 6: General Discussion

Inactivity levels among the SCI population are unacceptably high and the burden of non-communicable diseases needs to be defied (Cao et al., 2011; Collie et al., 2010; DeVivo et al., 2011; Martin Ginis et al., 2010e). Physical activity programs with ecological validity should be a priority for communities world-wide to guarantee the health and well-being of all their members (Bauman et al., 2012). Therefore, the purpose of this thesis was to study the development and implementation of a community-based physical activity program for people with SCI, addressing barriers and facilitating access to safe and supervised training. Findings from the dissertation studies improved understanding on why some individuals with SCI are inactive and uncovered efficient measures for behavioural change. Additionally, findings have implications for translational research and the use of Positive Psychology principals on the integration of a marginalised population and the promotion of quality of life improvements. The contribution to evidence based practice provided by the dissertation studies within this thesis are discussed in the following sections:

Section 6.1 Contributions to the understanding of barriers and facilitators to physical activity.

Section 6.2 Contributions to translational research: inclusive practices at the community level.

Section 6.3 Contributions to Positive Psychology and the study of personality attributes.

6.1 CONTRIBUTIONS TO THE UNDERSTANDING OF BARRIERS AND FACILITATORS FOR PHYSICAL ACTIVITY

Understanding factors that influence physical activity participation is the first step towards effectively assisting a person with SCI to become active. Barriers to physical activity need be identified and plans that facilitate it must be actioned. This study revealed important barriers according to a sample of 85 individuals with SCI in Australia and New Zealand and differences between perceived barriers and actual barriers. Interviews before and after a customised physical activity program (i.e. SCIPA Com) showed that factors commonly believed to be important impediments before SCIPA Com, such as motivation, physical and psychological barriers were in fact secondary when compared to health complications, lack of transportation, costs, and information related barriers after actually being involved in physical activity.

Knowledge of one's background in sports and physical activity participation before and after a SCI is a strong indicator of future practices (Bauman et al., 2012). The sooner people were involved in physical activity the higher were their chances in adopting healthy practices. In the clinical setting, this suggests that rehabilitation professionals such as doctors, nurses, physiotherapists, and occupational therapists need to recommend and stimulate physical activity early on in their patients' rehabilitation phase. Ideally, recreational physical activities should be properly taught during rehabilitation and emphasised before patients are discharged from health services. Guidance from health professionals as to where people with SCI can continue their LTPA programs in the community is also paramount.

A referral system was established by SCIPA Com researchers in order to address miscommunication present between hospital services and community fitness centres. Health professionals from SCI units across Australia and New Zealand were associated to SCIPA Com to provide an option for community dwelling individuals with SCI in maintaining adequate physical activity levels. Several researchers previously supported the implementation of referral systems and confirmed their efficiency in increasing physical activity levels among the general population (Moore et al., 2011; Pelletier et al., 2014; Rimmer & Henley, 2013). As for people with SCI living in the community for several years, information related barriers were one of the main impediments for it was common to assume there were no programs directed to people with SCI and the few available were poorly advertised by mainstream media. In this study, SCI networks, help and

support groups, as well as disability sports associations were informed and actively participated in the recruitment of participants in SCIPA Com. The fact that over 80% of participants in the previously inactive group completed training with SCIPA Com indicates the importance of establishing a connection between hospitals, SCI support systems and the community.

As recommended by previous studies (Cowan et al., 2013; Elley et al., 2007), SCIPA Com was concerned with preparing fitness centres to receive people with SCI. These fitness facilities were assessed for accessibility and action plans established to overcome barriers. Exercise professionals received training and guidance to work directly with clients with SCI. Physical activity programs were further facilitated via financial support associated to training (e.g. gym membership, personal training, transport, small equipment such as hand-grippers and ramps), as well as through a customised approach, integrating physical strengths, personality attributes and goals of clients into their program. Finally, clients were instructed on appropriate and safe execution of exercises in fitness centres and independently at home.

Whilst in the community setting, a sub-analysis on barriers perceived by the previously active population with SCI showed small to no changes before and after SCIPA Com, whereas the inactive population varied on many aspects. The active population consistently attributed difficulties regarding financial constraints, secondary health problems, and social barriers such as family and work commitments. The only barrier that seemed to become more evident among those already active within community fitness centres was accessibility issues, mainly due to non-accessible equipment and, in some cases, due to the presence of stairs, absence of accessible bathrooms, or lack of transportation. Motivational barriers, considered by previous researchers as the main obstacle to physically active life styles (Cowan et al., 2013; Kehn & Kroll, 2009), were also stable in the pre and post evaluations of the active sample.

In contrast, motivation improved among the inactive group after partaking in SCIPA Com, showing that prompting the SCI population with opportunities and support assists on perception changes towards physical activity. Instead, barriers of different natures prevailed. Among them figured secondary health problems, transportation logistics, and lack of mainstream interest in assisting people with disabilities.

6.2 CONTRIBUTIONS TO TRANSLATIONAL RESEARCH: INCLUSIVE PRACTICES AT THE COMMUNITY LEVEL

Translational research has been classified as a priority in many high profile academic, research, industrial, and health related institutions, receiving a large injection of money over the last decade (Woolf, 2008). The definition of translational research lacks clarity and could benefit from a grading system on the degree to which they are translational (De Maria, 2013). Most translational studies in SCI are classified as basic or pre-clinical experimental designs (Kwon, Hillyer, & Tetzlaff, 2010). These require laboratory-based scientists with a set of basic/fundamental science skills to investigate the development of pharmacologic treatments, transplantation of cells/biomaterial into the spinal cord, axonal growth or sprouting, gene therapy, and/or stimulation of neuroplasticity.

Other types of translational research convey findings from laboratory experiments into the community setting, preferably following recommendations from established systematic reviews and/or guidelines (Woolf, 2008). SCIPA Com program falls within this scope of translational research in the community. As detailed in **Chapters 3 to 5**, studies within this thesis disseminated evidence-based information, translated and transferred knowledge to exercise professionals, and made a public health initiative available for the SCI population. Perhaps the best definition for this type of research was provided by the National Institutes of Health (2014): translational community engagement and research is to “foster collaborative research partnerships and enhance public trust in clinical and translational research, facilitating the recruitment of research participants from the community”. Though translational studies are subjected to more external influences that cannot be entirely controlled, they are the means to access cutting edge knowledge and services in the real world.

The majority of neuroprotective and neuro-regenerative SCI therapies based on basic science research of the past thirty years have not provided sufficient evidence for wide-spread acceptance (Kwon et al., 2010). Fortunately, clinical SCI research related to the management of secondary health conditions and physical functioning has been more successful. Drastic advances have been made on the treatment of pressure ulcers (Krause & Broderick, 2004), respiratory care (Berlowitz & Tamplin, 2013), infections, and pain (Nandoe Tewarie, Hurtado, Bartels, Grotenhuis, & Oudega, 2010) that were once responsible for high mortality rates.

Interventions have also emphasised general well-being improvements through social integration, psychological assistance, and physical activity among people with SCI (Davis, Kumaran, & Nair, 2009; Martin Ginis et al., 2011a).

Within physical activity intervention studies for people with disabilities, only recently have they been trialled in the community setting and, until now, it was limited to the North American population (Block et al., 2010; Froehlich-Grobe et al., 2014; Latimer-Cheung et al., 2013; Latimer et al., 2006a; Wise et al., 2009). SCIPA Com was the first community-based program that involved SCI cohorts from Australia and New Zealand. This initiative covered procedures from the establishment of an organised referral system from institutionalised care to the delivery of tailored LTPA programs in the community setting by local service providers. Therefore, SCIPA Com proved to be an effective ecological model that can be implemented across many locations in both countries, promoting long-term physical activity participation and further social integration among people with SCI. In the future, this model can be extrapolated to other forms of disabilities.

As recommended by Martin Ginis et al. (2012i) in their study on community-university multidisciplinary partnership approach, we interviewed participants uncovering important issues and necessities among people with SCI; combined efforts with credible health and fitness organisations, such as the YMCA; provided exercise professionals with educational material and support (online and didactic knowledge translation and transfer); redirected focus to the strengths presented by clients with SCI; facilitated (cost and support-wise) gym access to individuals with SCI; and assessed the effectiveness of the program via improved health outcomes (i.e. LTPA levels, quality of life and functional satisfaction) in the SCI population. Assessments provided novel information on self-esteem measures through the RSS, before and after an eight-to-twelve weeks physical activity program.

Enhanced LTPA and quality of life measures obtained in this research's population compared to previous studies corroborate the procedures adopted. Lessons from evidence-based physical activity guidelines (Martin Ginis et al., 2011a; Myslinski, 2005; Sasso & Backus, 2013) and the demand for more accessible forms of activities in the community (Rimmer, 2005; Rimmer & Henley, 2013; Rimmer & Marques, 2012) were assimilated into SCIPA Com. The main differences in our approach were the integral involvement of clients with SCI in decision making, customisation of physical activity programs according to their strengths, and improved accessibility to fitness centres in their local community (i.e. in suburbs and rural towns). These were found to increase physical activity levels, though long-term

participation was reliant on costs associated to training. Further improvements need to be actioned to provide financial assistance and knowledge mobilization in the community, factors known to present strong association with engagement among the SCI population (Cowan et al., 2013; Gainforth et al., 2014).

In order to ensure the success of community-based projects, collaborations between credible educational institutions and strong leaderships in the community were essential. Martin Ginis et al. (2012i) explained that this means aggregating and involving the right people for the task in case. High adherence rates obtained throughout SCIPA Com and significant improvements in all outcomes assessed were greatly a result of advocacy measures on behalf of people with SCI by funding bodies, academics, health care professionals, managers of community fitness institutions, and especially by exercise professionals on the forefront physical activity service delivery. Along with improved health benefits, community-based programs increase the awareness to the needs people with SCI and other types of disabilities, taking further steps towards an equitable society.

Based on the positive results obtained in the preliminary stages of SCIPA Com, the following recommendations are proposed for future translational research and practice:

1. Formalise partnerships and ongoing collaborations between credible educational institutions and the fitness industry within the community;
2. Promote events in the community and disseminate the guidelines on physical activity and healthy living behaviour among people with SCI and community service providers, such as staff members of a fitness centre;
3. Implement evidence based practices within community services and fitness centres to deliver better services to those with a spinal cord injury (through the NDIS if applicable); and
4. Widespread practice change within community centres and individuals with SCI living in the community.

6.3 CONTRIBUTIONS TO POSITIVE PSYCHOLOGY AND THE STUDY OF PERSONALITY ATTRIBUTES

Positive Psychology is based on the principle of stimulation and enhancement of personal strengths to achieve improved outcomes as opposed to focusing on the weaknesses or pathologies of an individual (Seligman & Csikszentmihalyi, 2000). Literature suggests that personality attributes are malleable characteristics and can be nurtured in supportive environments to progress in the fields of health, education, and relationships (McAdams & Pals, 2006; Park & Peterson, 2009; Peter et al., 2012). Though a few studies had identified encouraging results among students, teachers, and people recovering from illnesses (Park, 2004; Park et al., 2004; Park & Peterson, 2009), none had attended to the understanding of socio-behavioural mechanisms of personality attributes among the SCI population. The present research was the first to direct attention to the study of positive personality attributes in people with SCI that promote a vital component of healthy lifestyles: physical activity participation.

This study's SCI cohort revealed personality attributes related to increased physical activity participation and measurable predictors of long-term activity behaviour. The Positive Personality Attributes Scale for Clients with SCI provided an internally reliable measure of attributes entailed in the physical activity context from the perspective of individuals with SCI and exercise professionals. The scale highlighted the importance of ones' self-perception regarding motivations to engage in physical activity, underpinned by a sense of commitment to their program and exercise professional, confidence in their abilities, and focus in achieving realistic goals. Further importance was attributed to ones' past experience in sports or physical activity for the prediction of participation in the long-term. Those involved in physical activity before SCIPA Com were more likely to continue high levels of training after an intervention, suggesting once again the necessity of early training during the rehabilitation phase and soon after discharge from hospital services.

As for exercise professionals, findings improved the understanding of motivational forces that facilitate physical activity participation among clients with SCI. Positive rapports need to be established between trainers and clients through mutual respect and cooperation. Exercise professionals with knowledge in SCI are more equipped to direct these clients throughout safe activities that enhance physical abilities and strengths, and nurture their sense of accomplishment by

setting challenging, yet achievable goals. This requires the incorporation of their clients' objectives and autonomy in the development of customised physical activity programs. Additional support might be necessary to motivate female clients and individuals who have sustained SCI for prolonged periods of time. These factors were found to have an inverse association to physical activity levels.

Perceptions of outsiders, represented by those of exercise professionals in this study, had no significant influence over physical activity behaviour of people with SCI. This may suggest a stronger sense of awareness on behalf of the SCI cohort or unattainable comprehension of what it means to sustain a disability if one has not experienced it. Perhaps the best health care professionals can aim for is to listen and assimilate their client's preferences, needs, and strengths as much as possible in their treatment and daily practices. Further research is required to examine the construct validity and reliability of the Positive Personality Attributes Scale. Finally, attributes need to be analysed individually to identify the extent to which each one of them influences physical activity behaviour and how service providers can utilise this information effectively on the development of health strategies in the community.

Chapter 7: Conclusions

A multi-centre investigation of barriers to physical activity in Australia and New Zealand identified changes towards perceptions of barriers to physical activity especially among inactive individuals with SCI. Accessibility issues were consistently reported by active and inactive individuals, as well as financial constraints and secondary health complications. On the other hand, a customised physical activity intervention in community fitness centres (i.e. SCIPA Com) which also accounted for the physical strengths, personality attributes, and goals of individuals with SCI, facilitated physical activity participation, and increased motivation within the SCI cohort analysed. Among those considered physically inactive before SCIPA Com, perceptions regarding costs, physical, and psychological limitations reduced and many realised that lack of information and costs were the main reasons they were inactive in the first place. This emphasises the role health professionals have in guiding patients with SCI on the proper execution of exercises and facilitating a healthy transition back into society by engaging community-based organisations. Government and private funding bodies need to be actioned for the sustainability of such practices.

The health promotion model proposed by SCIPA Com presents ecological validity through the direct involvement of community-based service providers: exercise professionals. They were considered catalyst forces in motivating previously inactive individuals with SCI to engage in LTPA. Participants presented improved quality of life, functional satisfaction and self-esteem as a consequence of improved LTPA levels. Enduring effects were detected after intervention in approximately half of the inactive individuals included in the program. Further measures are warranted to assist individuals that did not adhere to physical activity in the long term.

Based on the findings of the three studies performed within the SCIPA Com program, the following practices associated to improved physical activity participation are recommended:

- **Financial support and improved accessibility for individuals with SCI:** Substantial changes in terms of policy and infrastructure need to be implemented to ensure availability of programs for populations at a higher risk of inactivity throughout an extended period of time. DisabilityCare

Australia (the NDIS) or ACC in New Zealand should be considered to access the necessary funding and ensure the longevity of initiatives such as the SCIPA Com model.

- **Establish an organised referral system to inform outpatients (through SCI networks, hospitals, SCI units, or clinics) about physical activity opportunities in their communities:** Rehabilitation professionals, social workers, and academics are advised to inform and mediate the process of community re-integration of individuals with SCI via community fitness centres.
- **Partnerships between credible educational institutions and the fitness industry:** Collaborations between academics and organisation such as the YMCA should be formalised to increase the credibility and availability of public health initiatives targeting the SCI population. SCIPA Com is a public health model that can be adopted by several community fitness centres in Australia and New Zealand, or adapted to other locations. The exercise professionals contacted for this purpose should be oriented on safe and efficient delivery of a physical activity programs in the community. Preferably, exercise professionals ought to be trained and provided with support from academics, rehabilitation professionals, and experienced exercise professionals to increase their knowledge and experience in working with the SCI population.
- **Increase community participation:** Further awareness and knowledge-transfer events on physical activity guidelines and healthy living among people with SCI should promote more participation from community service providers and society as whole.
- **Integral involvement of clients in the development of physical activity programs and decision making, as well as the inclusion of measures that boost positive personality attributes:** Our findings suggest that exercise professional need to foster positive attributes among clients with SCI, such as motivation, confidence, commitment, adaptability, realistic expectations, patience, competitiveness, and knowledge on how to exercise and associated benefits. Understanding how interest, accomplishments, and experiences are stimulated in clients with SCI could lead to higher levels of motivation and improved physical activity behaviour. Their direct involvement in the development of their

physical activity program increases their participation. Further research is required to determine these mechanisms and whether interrelationships between exercise professionals and clients with SCI influence on physical activity outcomes.

- **Future studies focused on sub-populations with SCI at a higher risk of inactivity:** SCI populations with advanced age or of the female gender require further programs that are appropriate to their interests and requirements.

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Appendices

Appendix 1 Information Sheets and Consent Forms

INFORMATION SHEET FOR PARTICIPANTS WITH SPINAL CORD INJURY

Barriers and Facilitators to Physical Activity among Individuals with SCI

Supervisors: Professor Garry T Allison, Professor Mary Galea, Professor Sarah Dunlop, and Professor Alexandra McManus

Researcher: Beatriz Ito Ramos de Oliveira

Purpose

Physical Activity is important for individuals with spinal cord injury (SCI) to maintain both physical and mental wellbeing, however many barriers prevent them from undertaking physical activity programs within community fitness centres. These barriers include access issues, unsuitable equipment and assistance, and other obstacles that need to be identified and removed. The purpose of this study is to determine what helps or prevents people with SCI to participate in physical activity. You will be asked to fill out a questionnaire and to take part in an interview. This project is part of a national study called Spinal Cord Injury and Physical Activity in Community program (SCIPA Com) that aims to increase the level of activity and participation of individuals with SCI living in the community.

Who can participate

To participate in this project you must:

- Be 18 years old or older;
- Have a spinal cord injury that occurred at least 24 months ago;
- Be living within the community, that is in residential areas and not living in hospitals or rehabilitation facilities.

What is involved

The researcher will explain the questionnaire and the interviews involved in this project. If you wish to participate in this study you will initially be asked to complete the Barriers to Physical Activity and Disability Survey (B-PADS) to identify barriers towards physical activity.

Subsequently you will be interviewed on what you consider to be barriers and facilitators to physical activity for people with SCI in community exercise facilities. Your answers will be recorded with a digital voice recorder and later transcribed to identify the main barriers and facilitators for physical activity. The recordings will be safely kept for a period of seven years and destroyed after this period.

Finally participants will be asked to list individual characteristics of a fitness trainer and of an individual with SCI that are considered significant to increase physical activity and participation of people living with SCI in the community.

Confidentiality

Your personal information will only be accessible to members of the research team. It will be electronically stored in a password protected locked facility at Curtin University.

Anonymity and Identifiable Participants

Questionnaire answers will be collected anonymously, and individual scores will not be identifiable or made available for any purpose. Any information which may potentially identify you will not be used in any publication.

Withdrawal from the project

Participation in the project is completely voluntary. You may withdraw at any time and do not have to give a reason.

Risks/benefits to participants

There are no risks involved in this study. Benefits are expected to arise from the information obtained in this study by identifying barriers to physical activity participation for people with SCI and helping elucidate how to reduce or eliminate them. The aim is to lead to improvements in health and quality of life.

Further information

If you require further information, please contact Beatriz Oliveira (phone: 0416 288 897 or beatriz.itoramos@postgrad.curtin.edu.au).

Ethics Approval

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number PT0190/2011). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

CONSENT FORM

I _____ (first and surname) have read the summary of the **Barriers associated with physical activity and gym access for individuals with spinal cord injury** study and any questions I have asked have been answered to my satisfaction. I agree to participate in this activity, realising that I may withdraw at any time without reason and without prejudice.

I understand that all information provided is treated as strictly confidential and will not be released by the investigator unless required by law.

I agree that research data gathered for the SCIPA Com program may be published; I acknowledge that any personal information will be de-identified.

Participant's signature: _____

Date: _____

Researcher's signature: _____

Beatriz Ito Ramos de Oliveira

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number PT0190/2011). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

**Appendix 2
Barriers to Physical Activity and Disability Survey (B-PADS)**



Participant ID #: _____ **Initials:** _____ **Date:** _____

Date of Birth: ___/___/___ **Weight:** _____ kg

Gender

Male Female

Level of injury: _____

Complete Incomplete

Physical Activity Level

Active _____ hs/week Inactive

(To be considered active you must perform activities for fitness or entertainment purposes, besides transportation and other daily life activities.)

Assistive devices (Check all that apply): Walker Braces Cane

Wheelchair Electric Wheelchair

Use of arms (Check one): Full Partial No Use

Use of legs: Full Partial No Use

Participant ID #: _____ Initials: _____ Date: _____

BARRIERS TO PHYSICAL ACTIVITY AND DISABILITY SURVEY (B-PADS)

1. Would you like to begin an exercise program?

Yes No Already in an exercise program

2. Have you ever exercised?

Yes No

2a. IF "Yes" Did you ever have any health problems that caused you to stop exercising?

Yes No

3. Have you ever been injured from exercising?

Yes No

4. I have gone to a fitness centre, but it was not a positive experience.

Yes No

4a. If "YES" why?

5. Have you ever exercised regularly?

Yes No

6. Do you know of a fitness centre that you could get to?

Yes No

6a. IF "Yes", would you like to go there to exercise?

Yes No

6b. IF "Yes" Would you have a means of transportation to get there?

Yes No

6c. IF "Yes" Would you have to pay to be transported to the exercise facility?

Yes No

6d. IF "Yes" Could you afford to spend this amount of money?

Yes No

7. Would you be willing to spend this money?

Yes No

8. Would you have any concerns about exercising in a facility like a YMCA or community gyms?

Yes No

8a. IF "Yes", what are your concerns?

9. Do you feel that an exercise instructor in a fitness centre like a YMCA would know how to set up an exercise program to meet your needs?

Yes No

10. Do you feel that an exercise program could help you?

- Yes No

11. Are you ever afraid to leave your home?

- Yes No

12. Has your doctor ever told you to exercise?

- Yes No

12a. IF "Yes" Did your doctor tell you to do anything specific?

- Yes No

12b. IF "No" Has your doctor told you not to exercise?

- Yes No

13. I am satisfied with my physical appearance, so I do not need to exercise.

- Yes No

14. Family responsibilities prevent me from exercising as much as I would like.

- Yes No

15. My job prevents me from exercising as much as I would like.

- Yes No

16. Are any of the following statements, concerns why you might not be involved in an exercise program or not exercising as much as you would like? (You can mark as many as you think are relevant)

- Cost of the exercise program
- Lack of transportation
- Lack of time
- Lack of interest
- Lack of energy
- Lack of motivation
- Lack of support from friends or family to exercise
- Lack of a personal care attendant who will help me exercise
- Lack of accessible facility
- Exercise is boring or monotonous
- Exercise will not improve my condition
- Exercise will make my condition worse
- Exercising is too difficult
- Don't know how to exercise
- Don't know where to exercise
- Health concerns prevent me from exercising
- Incontinence issues prevent me from exercising
- Pain prevents me from exercising
- I am too old to exercise
- I am afraid to leave my house
- Feel uncomfortable or self-conscious in a fitness centre
- None of the above

17. Can you think of any other reasons why you might not be involved in an exercise program or not exercising as much as you would like? If so, please list:

Thank you for completing this survey!

Appendix 3 Study 1 Interview Questions

Participant ID #: _____ Initials: ____ ____ Date: _____

BARRIERS AND FACILITATORS FOR PHYSICAL ACTIVITY – SCI

Interview Protocol

My name is _____ (facilitator) and this is _____ (observer). We are both from _____.

We are here today to discuss the factors that influence the practice of physical activity. The discussion will centre around your perceptions and experiences relating to barriers and facilitators in physical activity.

Before we start our interview, you will notice a consent form in front of you. Read through the details on this form. If you are happy to be involved in the interview please sign the consent form and return it to the interviewer.

Do you have any questions or comments before we start?

Just before we get started I would like to go through some information about the procedure of the interview.

Interview Rules

Confidentiality

We are recording this session. This is because we consider all the information you provide us is important and don't want to miss any of it. The information will be typed up and you will not be identified in any reports from the study.

Honesty

Please answer the questions honestly. There are no right or wrong answers and we are interested in hearing your opinion. Tell us what you really think and feel not what you think you should feel, or what you think we want to hear.

Freedom to Leave

If you are uncomfortable with anything that we talk about at any time please feel free to not answer the question or leave the room.

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number PT0190/2011). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

Participant ID #: _____ Initials: ____ Date: _____

INTERVIEW GUIDE FOR PARTICIPANTS WITH SPINAL CORD INJURY

Did you practice any physical activity before your spinal cord injury? (Physical activities are those done during free time, such as wheeling, playing sports, or exercising at a gym, not including daily activities that involve manual wheelchair use for mobility or work.)

When did your spinal cord injury happen and what was the cause of it?

How was your rehabilitation experience after your spinal cord injury? (Do you feel like you learnt how to manage yourself and how to do physical activity?)

Have you practiced any sports or physical activity after your injury?

What type of sports or physical activity do you practice and how often do you do them?

What are the barriers that stop you from practicing a sport or physical activity? (Barriers are the reasons why people with spinal cord injury do not practice physical activity, such as non-accessible buildings, pain, costs, not enough motivation or energy, lack of information, health complications, etc.)

What facilitates the practice sports or physical activity?

How does physical activity help you with secondary problems, such as pressure ulcers, bowel proگرامing, urinary tract infections, diabetes, cardiovascular disease, obesity, and orthopaedic complications?

Do you ever experience pain? What are your strategies to relieve your pain?

What are your future plans considering sports or physical activity training?

**Appendix 4
Study 1 Coding Manual**

Experience with physical activity before SCI		
Active Group		
Theme	Theme Description	Examples of Quotes
<i>Yes, everyone in the active group was exposed to a variety of physical activities and sports before their SCI.</i>	Active individuals practiced a variety of sports before acquiring a SCI: aqua aerobics, athletics, Australian football, badminton, basketball, bowling, boxing, cricket, cycling, darts, farming, gardening, golf, fitness training, hiking, hockey, kayaking, martial arts, motorcycling, netball, rock climbing, rugby, running skateboarding, skiing, soccer, softball, squash, surfing, swimming, tennis, triathlon, volleyball, walking, water skiing, and wrestling.	<p>“Yes, I do it regularly all my life. Actually I was involved with some sport - soccer, martial arts and I work out on my fitness and body, and swimming.” (SC04)</p> <p>“Number one was boxing obviously, then I was doing gym work, swimming, I used to love swimming, running a lot, that sort of exercising.” (SC055)</p>
Inactive Group		
Theme	Theme Description	Examples of Quotes
<i>Yes, a few people in the inactive group were exposed to a few types of physical activities and sports before their SCI.</i>	Participants from the inactive group reported less variety and intensity of sports participation, though a few had experience practicing basketball, cycling, fitness training, swimming, tennis, walking, hockey, netball, rowing, water-skiing, and cricket.	<p>“I did some sports. I did a bit of tennis and I enjoyed swimming and some bike riding, but that was the limit.” (SC042)</p> <p>“I was going to the gym twice a week which included mainly the treadmill.” (SC068)</p>
<i>None. One individual had never been involved with physical activity.</i>	One individual had never been involved with physical activity.	<p>“No. I like sport but I've never participated, never - always been a bit uncoordinated.” (SC063)</p>

Experience with physical activity after SCI (and before SCIPA Com)		
Active Group		
Theme	Theme Description	Examples of Quotes
<i>Yes, all participants in the active group were already involved in physical activity.</i>	After acquiring a SCI, people in the active group reported having experience with endurance and strength training, flexibility exercises, swimming, hand cycling, athletics, basketball, rugby, kayaking, archery, sailing, hockey, and lawn bowling.	"I started playing wheelchair basketball. At the same time I also played wheelchair rugby. Then I got into hand cycling." (SC002)
Inactive Group		
Theme	Theme Description	Examples of Quotes
<i>Yes, some participants in the inactive group were exposed to physical activity though they were not active at the time.</i>	<p>People in the inactive group were exposed to less types and time of physical activity, though some reported having experience with strength training, stretching exercises, swimming, handball, tennis, rowing, and wheelchair rugby.</p> <p>Many lost interest after a certain period.</p>	<p>"Ah, just basically my general health and wellbeing - building up my muscles. Just building my upper body strength." (SC035)</p> <p>"Yes, it was the first few years after, say about four or so years ago, I decided to do something. I started off with handball just for a few months and then I had started with the wheelchair tennis, which I'd done for a couple of years. In between I ventured into doing some rowing but I felt that that was a bit too much so it was pretty much wheelchair tennis but I haven't been playing this past." (SC061)</p> <p>"I did a little bit, then I lost interest." (SC036)</p>
<i>None. Two participants had not practiced any kind of physical activity post-injury.</i>	Two participants had not practiced any kind of physical activity post-injury.	"No. I like sport but I've never participated, never - always been a bit uncoordinated. (SC063)

Rehabilitation Experience

A combination of positive and negative perceptions about their rehabilitation program following SCI were reported by participants.

Active Group

Theme	Theme Description	Examples of Quotes
Positive	<p>The rehabilitation experience was deemed important to learn how to perform activities of daily living (ADLs) and how to exercise to obtain physical improvements.</p> <p>Many found their rehabilitation programs efficient and others were satisfied with their access to resources and information (e.g. information on adapted sports) that assist them with their disability.</p>	<p>"Yes, the daily life stuff. There was - we had some strength work in the spinal gym. Some physical activities and then we had some people coming in to show us lots of sports we could do. So we had people coming in with equipment like a javelin and shot put and discus and stuff." (SC013)</p>
Negative	<p>Participants perceived the rehabilitation experience as long, arduous and daunting.</p> <p>Many were not properly taught how to exercise.</p> <p>They were also confronted by the lack of information especially after discharge from rehabilitation services to continue exercising.</p>	<p>"Didn't really do any exercise in there apart from a small amount of work on an internal gym, most of it was just transfers, stretching your body, getting you used to various things that you needed to do once you got out of hospital." (SC002)</p> <p>"I think - when you go home from hospital you have certain needs and then a year or two years or even five years on from going home, your needs really change. That - you are probably left to your own devices. I probably could have used a bit more help with how to look after my body and keep fit. You are left on your own and there is not really any kind of contact with outpatients or that kind of thing... you just don't have any ideas of your own of how to begin the next stage of looking after yourself, being in a wheelchair." (SC066)</p>
Mixed	<p>People in the active group acknowledged the benefits gained from their rehabilitation experience, though this period was surrounded by uncertainties and distress.</p>	<p>"There's always good and bad in all aspects... It's a sudden shock going from being able to move to not being able to move. I adapted fairly quickly to my circumstances which helped." (SC047)</p>

Inactive Group		
Theme	Theme Description	Examples of Quotes
<i>Positive</i>	<p>Participants were satisfied with their rehabilitation experience due to:</p> <p>Good health professionals who helped them learn how to perform ADLs and exercises. Perceived physical and psychological improvements.</p>	<p>"I had really good physios, OTs and my nurse therapist was an absolute dragon lady that pushed me really hard. My OT she was great, she wanted to just, treated me with all sorts of things as an experiment to see how much I could do because I was incomplete. We tried all sorts of weird and wonderful things to do as much as I could to try and make myself as independent as possible. The physios were really good in assisting with that as well." (SC005)</p>
<i>Negative</i>	<p>Participants perceived their rehabilitation as:</p> <ul style="list-style-type: none"> • Emotionally difficult. • Insufficient rehabilitation in terms of quantity, time, and information. • Focused on ADLs and not on physical activity. 	<p>"... when you go home from hospital you have certain needs and then... your needs really change. I probably could have used a bit more help with how to look after my body and keep fit... There was a period there where you feel like you are a bit - not abandoned, but you just don't have any ideas of your own of how to begin the next stage of looking after yourself, being in a wheelchair." (SC066)</p> <p>"They taught you how to manage yourself... probably not exercise, but just keeping things stretched and moving, I suppose is sort of focussed on." (SC091)</p>
<i>Mixed</i>	<p>People in the inactive group also acknowledged the benefits gained from their rehabilitation experience, though it was a devastating situation for many.</p>	<p>"Well apart from being sad, it was good. I progressively improved and so it was - some mobility was coming back it was after about three or four weeks. That was rewarding, it sort of encouraged me to carry on." (SC042)</p> <p>"I suppose I learnt a few things. But the whole thing was negative and bad because of the situation, you know?" (SC056)</p>

Knowledge on benefits of physical activity prior to SCIPA Com

All participants associated physical activity to corporeal, psychological and social benefits.

Active Group

Active individuals had increased awareness of the physical and psychological benefits that stem from activity participation. Improvements were reported on energy levels and physiological functions (musculoskeletal, cardiovascular, respiratory, immunological, and gastrointestinal).

Theme	Theme Description	Examples of Quotes
<i>Physical improvements</i>	Benefits associated to physical activity were improved bowel management, general health, abilities, cardiovascular function, fitness, strength, weight loss, and improved sports performance.	<p>“I do it for the fitness that I get from my sport. So at my peak when I'm training for international competition I really notice my fitness levels increase tenfold and I feel better inside always and I can do a lot more work because I'm fitter.” (SC002)</p> <p>“Just stronger and fitter. Makes my transfers easier to do. My flexibility is a lot better. My muscles won't seize up as easy. I know in general I just feel better about myself and hopefully look better for my girl.” (SC036)</p>
<i>Psychological improvements</i>	Benefits associated to physical activity were improved well-being, enjoyment, feeling happier, focused, calm, and energised.	<p>“By doing the gym I find myself being a lot fitter, which helps with my positive outlook on things and my attitude to things can be a lot better.” (SC047)</p> <p>“Well, I find that the fitter I am, the happier I am and the less pain I have.” (SC066)</p>
<i>Prevention of secondary problems</i>	Physical activity was associated with the prevention of cardiovascular and metabolic diseases, pain, and fatigue.	<p>“It definitely helps with obesity and cardiovascular. I put a lot of pressure on my shoulders being in a wheelchair, so anything I can do to help limit that and just kind of fatigue. I think it helps, without being healthy, fatigue would be a bigger issue for me.” (SC065)</p>

Inactive Group		
Theme	Theme Description	Examples of Quotes
<i>Physical improvements</i>	Benefits associated to physical activity were improved bowel management, general health, mobility, fitness, strength, and weight loss.	<p>“The biggest benefit will be to prevent obesity, cardiorespiratory diseases and have a self-esteem boost with physical activity.” (SC031)</p> <p>“I think when you're fitter - when you're doing more activity, everything - every bodily function tends to operate in a more positive way. “ (SC051)</p>
<i>Prevention of secondary problems</i>	Physical activity was associated with the prevention of shoulder muscle imbalance and pain, cardiovascular and metabolic diseases, pain, and fatigue.	“... with the grinding motion I was using one particular muscle group. It's getting that muscle balance back into my body and so you're getting a balanced body instead of just developing one set of muscles. Also getting out into the sunshine and pushing around a lot more. Getting a bit more vitamin D and just physical exercise full stop is generally just good for your blood flow and your bowels as well and bladder” (SC005)
<i>Psychological improvements</i>	Benefits associated to physical activity were improved general well-being and attentiveness.	“It makes you more alert, it makes you more - for physical activity every time I've done physical activity I'm always more motivated to do other things whereas if I'm just sedentary... All I just feel like doing is moping around in front of television.”

Knowledge on benefits of physical activity post to SCIPA Com

Active Group

Benefits mentioned at baseline were reiterated during follow-up interviews. The active group continued to demonstrate a better level of awareness of health benefits compared to the inactive group.

Theme	Theme Description	Examples of Quotes
<i>Physical improvements</i>	<p>Benefits associated to physical activity were improved fitness, flexibility, mobility, physiological functions (e.g. cardiovascular), strength, balance, posture, reduced weight, and energy.</p> <p>These improvements also facilitated ADLs.</p>	<p>“I think my heart rate improved with some of the upper body work that I do.” (SC073)</p> <p>“It gives me strength to be able to walk better after I do physical activity. I feel as though I'm walking a lot better and moving a lot freer.” (SC052)</p> <p>“Other than losing weight and I'm sort of moving more freely than before. I don't have as much limitations of bending over and picking up stuff. When I had a big stomach I couldn't even bend over too much because it just physically stopped me to do it, you know? Now I've got nothing so I can easily pick up anything or move around quicker and my shoulders doesn't hurt as much on my transfers.” (SC055)</p>
<i>Psychological improvements</i>	<p>Benefits associated to physical activity were improved general well-being, self-confidence, mood, and motivation.</p>	<p>“It's helped me a lot because it's improving my - mentally, you know, I'm happier and more active.” (SC043)</p>
<i>Unknown</i>	<p>Some active individuals did not perceive improvements or did not present secondary health problems to comment on this question.</p>	<p>“I know physical activity makes me a fitter and healthier person, but no, I couldn't tell you how it's related to any of those headings you just mentioned, because I've got no knowledge of whether they help me with bladder, bowel, ulcers, or whatever. I've done it [physical activity] basically since I had my accident, so I don't know whether it's improved or not improved, if you know what I mean?” (SC002)</p>

Prevention of secondary problems	Physical activity was associated with the prevention of cardiovascular, respiratory, and metabolic diseases, as well as pressure ulcers.	<p>“Sport improves my heart and lungs and diabetes, helps with not building up excess sugar.” (SC013)</p> <p>“Yes, for sure it helps a lot. I had two pressure sores when we started this on my bottom, my backside. Now because - I'm sure there is, sort of you can link this up because I'm doing a lot of cardio. Also I had another, I still have another also down at my leg and my heel and that is dramatically improved in the last two months I'd say, ever since we started.” (SC055)</p>
Inactive Group Additional improvements were perceived among the previously inactive group.		
Theme	Theme Description	Examples of Quotes
Physical improvements	Benefits associated to physical activity were improved bowel management, fitness, functionality, strength, breathings, and weight loss.	<p>“Yeah, I was saying that the transfers are getting a lot better because I'm stronger.” (SC061)</p> <p>“Yeah well obviously the cardiovascular diseases, the exercise definitely benefits your heart and lung capacity. It's also a great benefit for your weight loss or keeping your weight in check. It also improves your circulation especially the cardio type exercises. Weight exercises or strength exercises obviously assist with your muscle tone and strength in certain areas... not to mention the - getting the endorphins flowing and improving your mental state as well so that's a big bonus.” (SC031)</p> <p>“Weight, I've lost about 10 kilos. I've also been trying to eat better. I think a fair percentage of it is diet, but the gym certainly helps because you use up calories or joules. Otherwise my breathing is - that would be the thing that's helped the most.” (SC059)</p>
Prevention of secondary problems	Physical activity was associated with the prevention of pain, infections, and weight gain.	<p>“I'm surprised at how much it has helped with my pain.” (SC036)</p> <p>“I barely have a urinary tract infection. I think it helps with the blood flow and that prevents pressure sores developing.” (SC037)</p>

Psychological improvements	Benefits associated to physical activity were improved motivation, general well-being, happiness, socialisation and self-confidence.	<p>“Well I want to talk about psychological because it has certainly given me more confidence because I had been becoming quite weak in the last two or three years - weak in the legs. I felt psychologically stronger and more motivated. I think that when I'm transferring that's also helped give me some strength.” (SC042)</p> <p>“Honestly with exercise wise and everything like that, it wasn't so much the exercise that had the ability to help me, it was actually getting confidence of actually being in a gym and being around other people. “ (SC039)</p>
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Barriers to physical activity prior to SCIPA Com		
Theme	Theme Description	Examples of Quotes
Accessibility barriers	Lack of facility access, adapted equipment, assistance, and efficient transportation were the general main concerns, especially among the inactive group.	<p>“[Lack of] greater availability of resources. For example, people that I know are unable to do any training anymore. After their rehab had finished that was it, and a lot of gymnasiums would not take them on, or personal trainers.” (SC052)</p> <p>“People to assist you getting in and out, weather and the rain” (SC001)</p> <p>“I know in the past I've actually rang a gym that's very close to my home and asked them if it was accessible. Or if it was - like the sports equipment were - like for example if you could move the bench and so someone in a wheelchair could use say a pull-down pulley thing. They said no, they can't do that. Although it was accessible to get into the gym, it just didn't facilitate - so I sort of gave up straightaway. I'm thinking a lot of the gyms are going to be similar sort of thing.” (SC061)</p>

Physical disability and secondary health problems	Diminished voluntary control of movements and loss of functionality limited the ability of both groups to practice sports or use certain equipment; as well as reduced energy levels, general illnesses, incontinence, pain, pressure ulcers, spasticity, UTIs.	<p>“Fatigue, no strength in the legs to actually carry me, the back injury is quite severe and any running or pounding does sort of reverberate through the body. So it's very difficult to get any sort of speed up. So you know physical activity like that is quite difficult.” (SC058)</p> <p>“See at the moment, I'm not strong enough. I can get myself across the road but I'm not strong enough to get myself up the hill on the way back. I have to get assistance because the hill is too steep.” (SC005)</p>
Information related barriers	Participants indicated the lack of specific information on physical activity programs tailored for people with disabilities in the community.	“Lack of knowledge, I suppose, with what can I do or how can I do it? Or what kind of machine could I use or?” (SC056)
Weather barriers	Adverse weather conditions repeatedly figured as barriers across groups.	“When I'm a lot fitter I can generally get myself up that hill unless it's raining of course and then I can't.”(SC055)
Financial barriers	Financial constraints figured as a significant barrier, especially among the inactive population.	“Well, the main one would be ongoing cost expense, being on [a fairly small] pension, and then you add anything in that costs.” (SC035)
Psychological barriers	Emotional and motivational barriers had a significant role in physical activity participation, as well as lack of self-confidence and interest in adapted sports.	<p>“It's motivation. Motivation is a big thing. Maybe lack of goals and motivation.” (SC013)</p> <p>“Self -confidence really. Also it is really a thing of just getting used to being in the public again.” (SC039)</p> <p>“Some sports are impossible because of my [lesion] I suppose, having nothing from the hips down probably stops from riding a horse. I see some people, they get strapped onto them, but that wouldn't interest me if you couldn't ride it like it was done before the accident.” (SC002)</p>

<p>Social barriers</p>	<p>Individuals from the both cohorts described common social attitudes that provoked discomfort and frustration.</p> <p>Social life also affected time management due to family responsibilities, prolonged work hours, and time required for ADLs.</p>	<p>“I find I really just have to psyche myself up a bit and go... to the gym, because you do get stared at a bit, because people are like oh - and I don't go when it's busy because you don't want to hold people up with getting in and out of your wheelchair, when you are doing circuits, because they are really quick. You might only be doing 30 seconds or one minute on something and you don't want to hold the queue up.” (SC066)</p> <p>“Yeah, I'd say every day activities and appointments stopped me from getting into any routine, or even establishing any routine.” (SC042)</p>
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<p>Barriers to physical activity post SCIPA Com Over all, perceptions on barriers were reduced among the inactive group when compared to their beliefs prior to the program, whilst the active group was consistent with their initial observations.</p>		
<p>Theme</p>	<p>Theme Description</p>	<p>Examples of Quotes</p>
<p>Accessibility barriers</p>	<p>Following the training program, participants considered fitness centres architecturally accessible; however more attention was given to inaccessible gym equipment and lack of an efficient referral system linking rehabilitation services to fitness centres.</p>	<p>“I can't get on any machines. I can only do free weights. Thank god for [the exercise professional], she came up with some brilliant ideas. Cable machine is the only thing I can get on, but bench pressing and lat pull downs and stuff like that, that is impossible... thanks to [the exercise professional] because she came up with the whole range of exercises.” (SC055)</p> <p>“Not so much that weren't accessible but the way that the hospital set it up, or set me up, was kind of like you have to wait for a physio. It makes it seem like that physio is the only option and the only thing that will help you and no one else will understand. No, you can't go to the gym because - they don't actually give you reasons why you can't go to the gym, they just freak out because they think, I don't know, you're going to hit yourself on the head with a dumb bell or something. But they never really put me in a place where it's like a positive way...” (SC060)</p>

Information related barriers	<p>Participants emphasised the deficit of physical activity programs targeted for people with SCI and knowledge on the existent ones.</p> <p>Lack of knowledge in how to exercise was also a barrier.</p>	<p>One of our biggest issues is we just don't know what's out there. Because we live in the community and we don't associate so much with the hospital and people straight out of the hospital, we don't know what's on. A lot of the time, wheelchair sports are - unless you're going chasing them, they're not promoting anywhere. (SC047)</p>
Financial barriers	<p>The majority of participants remained conscious of the financial unpracticality of employing exercise professionals though their assistance was necessary or had issues paying for transportation to fitness centres.</p>	<p>"The need to have another person there to help with the exercise regime and then the cost of joining the - you know, doing the activities, joining the gym and then also the cost of getting to and from home to the gym. So it's quite a costly exercise in getting into a car when you're paying oh, like it's only sort of like 10 bucks each way but then if you include gym on top of that, when you're only on a pension it's quite a big portion of it." (SC035)</p>
Physical disability and secondary health problems	<p>Both groups reported physical limitations such as limited hand function as barriers. Infections and general unwell states were the main causes of nonattendance, as well as lack of energy and injuries.</p>	<p>"A general feeling of unwell... There are days when the body just tended to shut down and I physically and emotionally couldn't be physical for want of a better word yeah." (SC058)</p>
Psychological barriers	<p>A reduced rate of psychological barriers was reported in both groups, although motivation remained a struggle for many.</p>	<p>"I don't always have the motivation to go to the gym. I can't do everything when I get there so sometimes I'm a bit frustrated, like some of the equipment I can't get access to is upstairs or it's not built in a way that I can use it." (SC038)</p>
Social barriers	<p>Commitments with carers, family and work challenged time management throughout the program.</p>	<p>"For me personally the biggest barrier is trying to fit it all in. By that I mean my work, my family life..." (SC001)</p>
Weather	<p>Rainy and cold days or extremely warm days.</p>	<p>"Over the winter it is always harder because I can't go out in the cold, in the winter. Summer I do it a lot more; I'll end up going out probably about three or four times a week for at least an hour-and-a-half each time". (SC047)</p>

Facilitators to physical activity prior to SCIPA Com		
Theme	Theme Description	Examples of Quotes
<i>Accessibility facilitators and information on them</i>	Participants believed that wheelchair accessible centres and equipment, personal assistance, and health and fitness programs targeted for people with SCI in the community would facilitate their physical activity participation.	<p>“Having those people around you and the right accessible equipment and facilities essentially. Always with wheelchair rugby we had a couple of other people would come down, our coach and other associated people down there would give you a lift in and out of rugby chairs - because I can't transfer in and out of my day chair - get strapped up and put special gloves on or whatever. So a similar sort of thing would need to be done in a gym environment.” (SC005)</p> <p>“Yeah, adapted equipment and I think information about the wheelchair sports network, where things have been set up for people in wheelchairs to participate... I think good access is really important. Like I went to a different swimming pool recently and the pool was a really long way away from the change rooms and involved quite a big push. That put me off and I went back to my other swimming pool, because when you are cold and you get out you just want to be able to be - get in and get out. You just want to be able to get back to the change room and get back to your car pretty quickly. It's funny, you are lazy about those aspects, but you are quite happy to go and do the exercise itself.” (SC066)</p>
<i>Affordability</i>	Subsidy for the acquisition of gym memberships and professional orientation was considered a paramount necessity.	<p>“... if it's given cheaper than normal, then that would be nice and helpful, but yeah it's a question of those things - trying to figure out what is going to be the cost and doing it - I suppose the cheaper it is, the more you're probably able to do it, but again it's a little bit of an unknown territory at this stage, because I'm not sure of the cost involved and yeah I'm just there to see what - see how it goes.” (SC035)</p>
<i>Physical ability</i>	The preservation of muscle control and activation were considered significant facilitators, as well as good general health.	<p>“I guess feeling good and being healthy at the time and also having - yeah having the time to practise and having the energy. Yeah I guess those are the things that would help me.” (SC061)</p>

<p><i>Psychological well-being and self-confidence</i></p>	<p>Both groups agreed on intrinsic factors as the main determinants, though motivation can be amplified through the establishment of specific goals, routine, and being held accountable for them over a determined period of time.</p> <p>Active individuals attributed their emotional draw to happiness and interest, whereas the inactivity group related it mostly to self-esteem.</p>	<p>“I’m quite motivated and quite competitive against myself. So if I’ve got a program and I’ve got goals that helps me.” (SC081)</p> <p>“I think the initiation - good initiation to it and some strong discipline to start off with. I’d need the discipline myself, to sell it to me that this is going to pay off. So that’s, I suppose, part of the motivation. Then once - if I started, within the two weeks, it would just fall into a system and I’d be able to negotiate my calendar of events, to slowly incorporate this as a routine, this is something that I do. I’d be really wrapped because that would increase my self-esteem.” (SC042)</p>
<p><i>Social</i></p>	<p>Company from friends or exercise professionals and specific times allocated for physical activity were great sources of motivation.</p>	<p>“I’m just used to playing team sports. I’ve never been one to just go to the gym by myself and work out by myself. I just find it boring but if I went to the gym with a couple of mates and all of that and we were together, then I’d do it.” (SC036)</p> <p>“I think if I had an enthusiastic and encouraging trainer. I think maybe having other people in a group, doing something in a group, is good.” (SC081)</p>

Facilitators to physical activity post SCIPA Com		
Following exposure to this program, the two groups confirmed their initial beliefs and observed additional facilitators.		
Theme	Theme Description	Examples of Quotes
<i>Accessibility facilitators</i>	Access to a local community fitness centres, equipment with removable seats, hand ergometers and exercise professionals with education in SCI were fundamental for the development of structured programs and guidance on safe execution of exercises.	<p>“Having local things set up so that people don't have to go - travel half a city away to get to.” (SC047)</p> <p>“The trainer was there the whole time with me, and there were some - I could only see a couple of pieces of equipment that was out of my reach, which I was able to reach with the help of the trainer... I had no issues with the car park or with the bathrooms or accessing any of the areas in the gym.” (SC061)</p> <p>“I think the fact that I wanted to get back into exercise again, and the personal trainer... was very easy to get on with. He realised that there was some things I couldn't do, there was limitations with the spinal cord injury but adapted the exercises to what I could do and what I couldn't do.” (SC068)</p>
<i>Information on available resources</i>	Aside from information facilitators originally mentioned (e.g. referral system), quality and quantity of information was further debated.	<p>“We [physiotherapist and patient] had a general talk and they put me on to two program possibilities and one of them was yours [SCIPA Com] which we followed up on and then some time later we started the three month program.” (SC042)</p> <p>“Well first of all you guys [SCIPA Com] - that's what it started with, it's as simple as that...” (SC055)</p>
<i>Good weather</i>	Mild climates and lack of rain favoured better and safer performances among individual with SCI.	<p>“Over the winter it is always harder because I can't go out in the cold, in the winter. Summer I do it a lot more; I'll end up going out probably about three or four times a week for at least an hour-and-a-half each time”. (SC047)</p> <p>“If it's a reasonable day, for example it's not 42 degrees or it's not pelting down with rain.” (SC005)</p>

Financial assistance	The main encouraging aspect of SCIPA Com was affordability to access fitness centres and exercise professionals.	"it's helped me by finding a place where I can go that's suitable and being able to fund it for me." (SC036)
Physical	<p>Participants with enhanced control over bodily functions were indeed more likely to engage in physical activity.</p> <p>Physical enhancements reflected on ADLs such as wheeling or walking further distances, transferring, and driving, as well as energy levels and breathing capacity.</p>	<p>"I think from a "cripps" perspective...the fitter you are...the fact is that life is just easier..." (SC001)</p> <p>"Changing of some of the exercises to further increase my strength and aerobic ability. What I've improved on still - I can - I'm going to increase all the activities of training to help that get better." (SC052)</p> <p>"... I can sit longer. One of the reasons that I stayed at home all the time was because I'm in so much pain that I can't move or sit... I can drive now." (SC060)</p>
Mental well-being	Enjoyment, self-confidence, and feeling comfortable in the environment were encouraging, along with perceived benefits to functionality and health.	<p>"I think more mentally than physically it helped me because I wasn't comfortable going to the gym prior to this program... So that [SCIPA Com] was just fantastic and the people that were in the gym were nice enough... They were actually quite receptive to someone who was, for want of a better word, gimp leg walking around in their gym. They didn't mind seeing something like that." (SC058)</p> <p>"... as I started this program then I started back to go back to the gym and I felt - I just felt great every time. Every single time I came out of there, I had the 45 minutes with [the exercise professional] and had a great training session, a lot of cardio. I just felt on top of the world every single time." (SC055)</p>

<p>Social</p>	<p>Both groups attributed importance to community participation and interactions with their exercise professional.</p>	<p>“Probably I could say also the fact that starting the program you had a personal trainer who was there to work with you to what exercises I could do. I don't know whether they're all the same but mine is very encouraging, very motivated and she spurs you on and she's chatty as well so that all helps. It's just encouraging. It's not off putting at all to go there.” (SC042)</p> <p>“Well, I think having been in this program has been great. Because having a personal trainer and a time really does make you go, because you're making that commitment and you don't want to let somebody down.” (SC066)</p> <p>“No, my thing was generally socially awkward and not having good self-esteem being in a wheelchair. Being new to being in a wheelchair was kind of like, it's like the pink elephant in the room because I'm in a wheelchair. I felt awkward just because of that. Also being able to socially interact with people that are fully functional whilst I'm sitting on a chair all day. You know that was the big thing that SCIPA helped me with as well. It made me look at the gym and say it's not just a death sentence from me being in a chair, it helped me a lot to get my confidence up and meet new people. Which helps me want to do more exercising and stuff too.” (SC039)</p>
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Experience in SCIPA Com		
Active Group		
Theme	Theme Description	Examples of Quotes
Positive	<ul style="list-style-type: none"> • Affordable. • Participants established a workout routine. • Exercise professionals had knowledge and training in people with SCI. • Identified fitness centres in the proximity of participants' homes. • Improved personal knowledge on how to exercise. • Physical improvements: strength, balance, cardiovascular condition, and function. • Psychological: improved confidence and outlook on training in the community. • Support from community and friendly environments. • Flexible physical activity program. 	<p>"It was a good one. I had really good experience because I improved lots of stuff, you know, and yeah, I spent a really nice friendly time here with the guys who is there. All the people are friendly and this program is good..." (SC043)</p> <p>"I have a very, very pleasant experience with the - specifically because of [exercise professional] as well. I think she's a great person as a trainer and I really like the whole exercise program. The way it was casual, it was very flexible, literally I could really go whenever I wanted to for that period of time and so... [exercise professional] was always available and she was there all the way. If I couldn't do anything she'd come up with some different way to do it, the same muscle group, so she was very adaptive to the training - to train me. I think she's got a lot of clients as well so she obviously is very good." (SC055)</p>
Negative	<ul style="list-style-type: none"> • Lack of adapted equipment in the fitness centres. • Active participants did not perceive improvements. • Shoulder injury due to excessive training. 	<p>"... but there is not enough equipment for us." (SC043)</p> <p>"...had I been someone who hadn't exercised and then done it for a lot longer - the timeframe probably wasn't that long either. The intensity probably wasn't enough to really measure it - for me." (SC057)</p> <p>"Well, some days I wish that I hadn't started it, because my shoulder probably wouldn't be like it is at the moment... I can see that it's probably a good idea to get people into the gym, but in my case, it's a little bit different." (SC002)</p>

Inactive Group		
Theme	Theme Description	Examples of Quotes
Positive	<ul style="list-style-type: none"> All were satisfied with their physical activity program and felt more motivated to participate. People in the inactive group appreciated working with an exercise professional with knowledge in SCI and learning how to exercise with them. 	<p>SCIPA Com] was more about doing a gym program as opposed to some sort of rehabilitative physio. It was more about a lifestyle option which is a better way to go. To me physio is like you do something until you get better or you don't get better. But somewhere along the line there's an end point... so this is more something that's got future and that's where huge benefit is. Also tying in with the local community - local provider that's been a huge benefit too. (SC042)</p> <p>For me it [SCIPA Com] meant that I might get more of a structured approach to getting some physio happening. Then after finding out more about it [SCIPA Com] - it was more about doing a gym program as opposed to some sort of rehabilitative physio. It was more about a lifestyle option which is a better way to go. To me physio is like you do something until you get better or you don't get better. But somewhere along the line there's an end point whereas... Yes so this is more something that's got future and that's where huge benefit is. Also tying in with the local community - local provider that's been a huge benefit too. (SC042)</p> <p>"the SCIPA program has actually made me want to get in the gym now and I have done that. I've signed up for another year at a gym." (SC039)</p>

Future plans prior to SCIPA Com

The plans for physical activity participation revealed overall concern with physical and psychological health.

Active Group		
Theme	Theme Description	Examples of Quotes
<i>Physical improvements</i>	Recover extra mobility; reduce weight, improve fitness; reduce pain; and be able to practice sports.	<p>“Probably just to maintain fitness and stay competitive. Maybe just travel, travel with the sport.” (SC013)</p> <p>“... some more racquet sports and try and have my - not just my upper body moving, but maybe try and move my legs a bit as well, so maybe just a little bit more variety. “ (SC081)</p>
<i>Psychological improvements</i>	Improve self-confidence and satisfaction with themselves.	“Get to know more people but also when we get comfortable that maybe then instead of just getting a sport or something like that to also expand on that as well.” (SC039)
<i>Socialisation</i>	Socialise with more people in the community.	“... because right now getting in to a gym and maybe making a few friends here and there we can both get a group outside of where I think I can just go out and be more comfortable in the community.” (SC039)
Inactive Group		
Theme	Theme Description	Examples of Quotes
<i>Engage in physical activity</i>	Participants expressed interest in engaging in a continuous physical activity program or sports and obtain physical improvements.	<p>“Well I'd like to get into a program and do it on a regular basis. If I can do it once or twice a week, that would be fantastic.” (SC068)</p> <p>“Well I really, really want to participate in sport or - whether it's my own sort of - my own physical training like for example in the gym.” (SC061)</p> <p>“Ah, at my age I just want to keep on maintaining what I've got physically for as long a period as I can maintain it, and have it as functional as possible.” (SC051)</p>

Future plans post SCIPA Com

Both groups wanted to keep improving their fitness levels, functionality, lose weight, prevent injuries, or trial other sports.

Active Group

Theme	Theme Description	Examples of Quotes
<i>Continuing their physical activity program or join sports.</i>	<ul style="list-style-type: none"> • Continue improving fitness levels, functionality, and practicing sports. • Weight loss and • Maintain physical activity levels to prevent injuries. 	<p>“Pretty much just seeing how it goes, just keep up my hand cycling for as long as I can and see where it goes from there.” (SC013)</p> <p>“my posture and that sort of thing - posture and lose weight. I seem to be in a continuous cycle of trying to lose weight.” (SC018)</p> <p>“I just think that having started a little bit of exercise it's made me realise how I really need to keep going at the moment. Because I'd sorted of reached a mark where I'd started a bit and I started getting a little bit fitter, but it makes you realise how unfit you really are. I'm still quite stiff, and I would really like to keep going so that I incorporate just some kind of exercise into every day. So some of that will be at home and some of that will be at the local pool or gym. I think it's been really, really worthwhile. So thank you for my three months of free personal training. (SC066)</p>
<i>Find funding to continue doing physical activity</i>	Participants were uncertain as to how they would fund their physical activity program.	“Well, that's a good question. We're actually looking to see - I think the group of us that are going to [exercise professional], want to continue and obviously there is no more funding from SCIPA, so we are investigating other - and as [exercise professional] is as well, investigating other options for funding.” (SC081)
<i>Socialisation</i>	<ul style="list-style-type: none"> • Travelling. • Helping other with SCI to become active. 	“... one is to do some travelling with my family and we're doing that at Christmas this year.” (SC058)

Inactive Group		
Theme	Theme Description	Examples of Quotes
<i>Continuing their physical activity program or join sports.</i>	Participants wished to continue supervised training to improve fitness levels, functionality, and join a sport.	<p>“Structured physical activity training with a proper instructor and a proper program, that's what I've been doing and I plan to keep up for as long as I possibly can... because that will only assist me in all aspects of my life, were it be from transferring to pushing, rolling over in bed, simply things like brushing my teeth. All sorts of areas, you know, keeping the strength and my upper body strength up assists me in all my daily living activities”. (SC005)</p> <p>“Again, I would like to keep this scheme up and running but it will come down to whether or not I can find someone that can do it with me on a regular basis and also the cost of going to do the scheme will be there as well.” (SC035)</p> <p>“I've got heaps of plans. Yes, definitely I want to continue to be active, I definitely don't want to do nothing. So I've got a few things lined up, like I said joining the gym, going back to tennis, and I want to go back to the pool as well, so I don't know where I'm going to find time to do all of this, but I will, I definitely will.” (SC061)</p>

Appendix 5

Study 2 Information Sheets and Consent Forms

INFORMATION SHEET FOR PARTICIPANTS WITH SPINAL CORD INJURY

SCIPA Com program

The main objective of the Spinal Cord Injury and Physical Activity in Community program (SCIPA Com) is to increase the level of activity and participation of individuals with spinal cord injury (SCI) living in the community. Physical Activity is important for individuals with SCI to maintain both physical and mental wellbeing, however many barriers prevent them from undertaking physical activity programs within community fitness centres. These barriers include access issues, unsuitable equipment, insufficient knowledge on SCI requirements to allow fitness trainers to design suitable physical activity programs, and other obstacles that need to be identified and removed.

The aims of this project are to provide a training program for fitness trainers about SCI, including appropriate goal setting and physical activity program design (2) To improve functional skills, exercise capacity, psychological wellbeing and community interaction in individuals with SCI through participation in a community-based physical activity program and (3) promote adherence to ongoing physical activity.

Who can participate

To participate in this project you must:

- Be over 18 years of age;
- Have a spinal cord injury that occurred at least 24 months ago;
- Have no recent fractures due to osteoporosis;
- Be screened by physicians for any kind of orthopaedic, cardiac or respiratory conditions that contraindicate the participation in physical activity;
- Be living within the community, that is in residential areas and not in hospitals or rehabilitation facilities.

Individuals will not be included in the physical activity program if they present full recovery of movement and function post-injury, and in case of uncontrolled pain and spasticity with movement.

What is involved

During the project you will be asked to:

- Work with a fitness instructor who has received training on SCI and physical activity considerations for people with SCI. Together you will set goals for a 12 week physical activity program. The fitness trainer will then design a physical activity program for you which will be approved by a Clinical Physiotherapist specialist in rehabilitation and SCI before you start training.
- You will attend a community-based exercise venue 2 or 3 times a week to participate in your physical activity program. The program will take 30-90 minutes to complete depending on your fitness levels. Your gym fees will be

paid for by the SCIPA Com program and transport costs to the venue are negotiable in case of limited resources.

- Before and after you start your 12 week physical activity program you will be asked to complete a questionnaire about your functional skills in activities of daily living, physical activity, psychological wellbeing, self-esteem, quality of life, and perceptions of efficacy. This will take approximately 45-60 minutes to complete.
- After the 12-week physical activity program, randomly selected participants will be contacted by their trainer at monthly intervals by telephone and asked about their current physical activity levels for 6 months.

Confidentiality

Your personal information will only be accessible to members of the research team, and will be electronically stored under password protection at Curtin University. Questionnaire answers will be collected anonymously, and individual scores will not be identifiable or made available for any purpose. Any information which may potentially identify you will not be used in any publication. Data collected will be used to assess the effectiveness of the physical activity program.

Withdrawal from the project

Participation in the project is completely voluntary and you may withdraw at any time for any reason without any negative consequences.

Risks/benefits to participants

You are subjected to standard risks of a physical activity program by participation in this project, namely mild muscular soreness and mild fatigue. The benefits to you are increased participation in physical activity and fitness if you complete the program.

Further information

If you require further information, please contact A/Prof Garry Allison (phone: 092 662 993 or g.allison@curtin.edu.au)

Ethics Approval

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR80/2010). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

INFORMATION SHEET FOR EXERCISE PROFESSIONALS

SCIPA Com program

SCIPA Com Program

The Spinal Cord Injury and Physical Activity in Community program's (SCIPA Com) main objective is to increase the level of activity and participation of individuals with spinal cord injury (SCI) living in the community. Physical Activity is important for individuals with SCI to maintain both physical and mental wellbeing, however many barriers prevent them from undertaking physical activity programs within community fitness centres. These barriers include access issues, unsuitable equipment, insufficient knowledge on SCI requirements to allow fitness trainers to design suitable physical activity programs, and other obstacles that need to be identified and removed.

The aims of this project are (Australian Human Rights Commission) to provide a training program for fitness trainers about SCI , including appropriate goal setting and physical activity program design (2) To improve functional skills, exercise capacity, psychological wellbeing and community interaction in individuals with SCI through participation in a community-based physical activity program and (3) promote adherence to ongoing physical activity.

Who can participate

To be involved in this project you must:

- Be a qualified fitness instructor with a minimum of 1 years practical experience
- Have permission from your employer to train people with SCI at your workplace

What is involved

During the project you will be asked to:

- Read and understand information in a training program that will involve both online and text elements divided into 10 units (approximately 10 hours total study required)
- Sit a multiple choice and short answer test at the end of each study unit (open book test, approximately 20 minutes to complete). This test is designed to evaluate your understanding of the material provided and is not a pass/fail test.
- Perform a disability access audit of your place of employment using assessment forms provided
- Work with an individual with spinal cord injury to set appropriate exercise goals and design an physical activity program for them
- Assist the person with spinal cord injury to complete their individual 12 week physical activity program
- Follow up some clients at monthly intervals for a period of 6 months to ask them about their current physical activity levels

Confidentiality

Your personal information and test results will only be accessible to members of the research team, and will be electronically stored at Curtin University under password protection. Data collected will be used to determine the effectiveness of the training program. Any information which may potentially identify you will not be used in any publication.

Withdrawal from the project

Participation in the project is completely voluntary and you may withdraw at any time for any reason without any negative consequences.

Risks/benefits to participants

You are subjected to no risk over and above your normal work practices by participation in this project. This is a free training program to enhance your knowledge on SCI and broaden your experience with adapted physical activity. These skills will enable you to attend a larger array of the population and promote a safe and inclusive environment in your work place.

Further information

If you require further information, please contact A/Prof Garry Allison (phone: 9266 2993 or g.allison@curtin.edu.au).

Ethics Approval

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CONSENT FORM – SCIPA COM PROGRAM

I _____ (first and surname) have read the summary of the SCIPA-Com program and any questions I have asked have been answered to my satisfaction. I agree to participate in this activity, realising that I may withdraw at any time without reason and without prejudice.

I understand that all information provided is treated as strictly confidential and will not be released by the investigator unless required by law.

I agree that research data gathered for the SCIPA-Com program may be published; I acknowledge that any personal information will be de-identified.

Participant's signature: _____

Date: _____

Researcher's signature: _____

Beatriz Ito Ramos de Oliveira

Ethics Approval

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR80/2010). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

Appendix 6

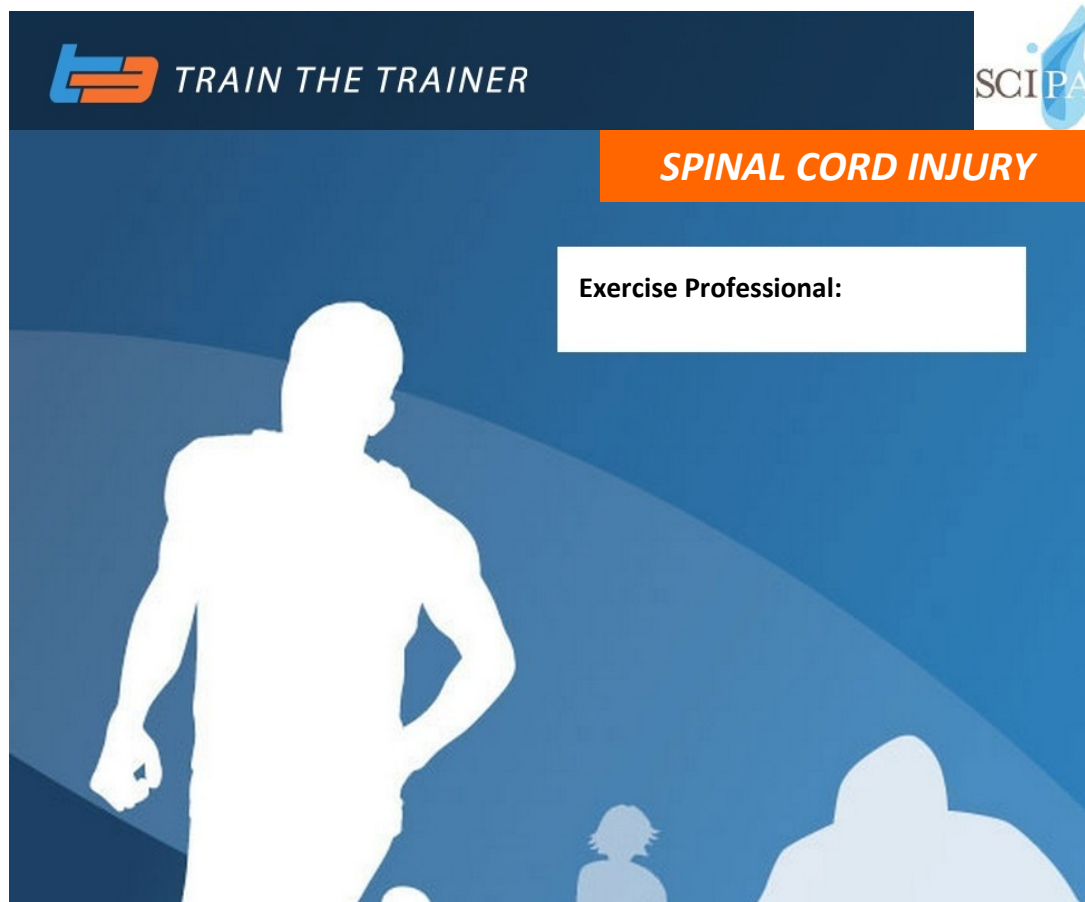
Train the Trainers Spinal Cord Injury Course® (T3-SCI®)

Facility access Checklist for Fitness Centres (Appendix 6.1); Pre-Training Risk Management Action Plan (Appendix 6.2), Examples of a physical activity programs for individuals with SCI in fitness centres (Appendix 6.3), T3-SCI Exercises Pictures (Appendix 6.4); and the T3-SCI Safety Procedures Booklet (Appendix 6.5) in the event of an emergency.

The T3-SCI® material was developed in association with researchers from Curtin University, the University of Western Australia, and the University of Melbourne. The PhD candidate (B.I.R.D.O) participated on the elaboration and delivery of the T3-SCI® course. The PhD candidate was responsible for providing didactic content and images, as well as editing the T3-SCI® website. Dr. Lousie Mofflin and Dr. Rebecca Crawford also contributed on the content and editing of the T3-SCI® website. Professor Garry T. Allison, Professor Sarah A. Dunlop and Professor Mary P. Galea reviewed and approved the T3-SCI® course. This course was further appraised and affiliated with the registration bodies for exercise professionals in Australia and New Zealand (*Fitness Australia and Registry of Exercise Professionals, respectively*).

Additionally, the PhD candidate delivered training sessions, assessments, and expert support for exercise professionals in her role as a Node Leader.

Train the Trainers Spinal Cord Injury Course® (T3-SCI®)



Your Node Leader:

Ph:

Email:

This project has been approved by the Curtin University Ethics Approval Committee (approval number HR80/2010). Curtin University Human Research Ethics Committee, Curtin University of Technology, GPO Box U1987, Perth 6845 ph: 9266 2784 email: hrec@curtin.edu.au.

CONTENT

Unit 1

Introduction and Goal Setting

Unit 2

Anatomy of the spine and nervous system

Unit 3

Spinal cord injury

Unit 4

Clinical and medical considerations

Unit 5

Disability act and disability awareness

Unit 6

Wheelchair and facility access

Unit 7

Safety, Risk management, injury prevention and emergency procedures

Unit 8

Exercise training following SCI

Unit 9

Designing an exercise program

UNIT 1 - INTRODUCTION

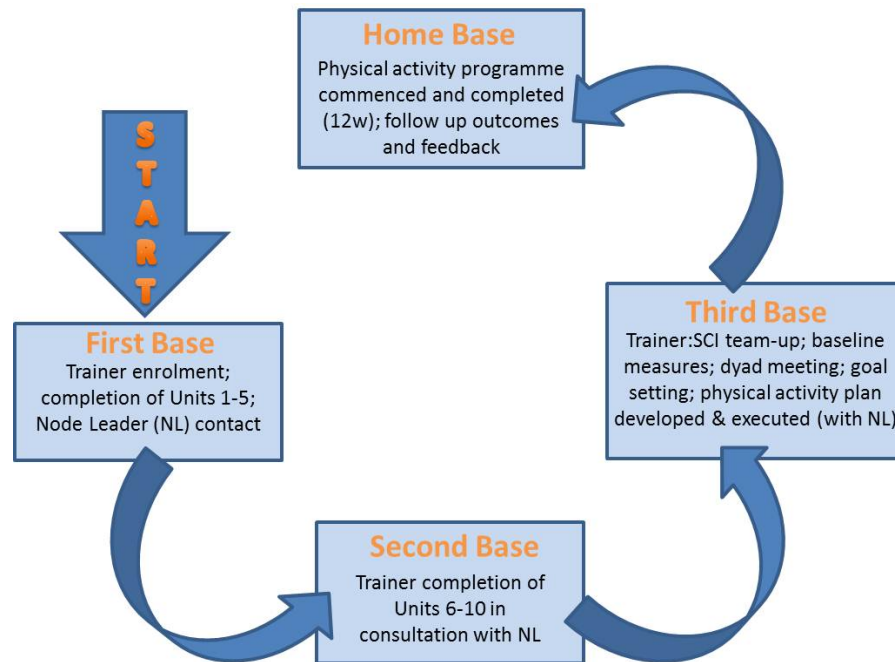
1. Congratulations on joining the Train The Trainer: SCI team (T3 SCI)!

Collectively we're a committed group of professionals with an interest in facilitating improved health and well-being for people with spinal cord injury. In particular, T3 SCI aims to increase the participation of people with SCI in physical activity in the community setting. While this may appear a simple endeavour, it is a complex and encompassing undertaking, yet one that intends to be rewarding for all involved. Well done for putting up your hand!

We hope to achieve our aims by:

1. Providing content knowledge of Spinal Cord Injury for people working in community Gyms.
2. Identifying the risks and factors that need to be considered when engaging with people who have SCI.
3. Initiating a system that improves access and safety for trainers, the organisation and people with SCI to perform physical activities in a sensible and appropriate manner.

Informed and enthusiastic fitness trainers are a significant and critical cog in the T3 SCI program's wheel. You have undertaken to educate yourself about spinal cord injury and physical activity-related knowledge. While it is acknowledged that the information in this education program represents a basic aspect of the complex topic of spinal cord injury, it is more than most people will know and as such on completion, puts you a big step ahead. The basic structure of the T3 SCI program is schematically represented in Figure 1.1.



Flow diagram outlining the primary stages in the T3:SCI programme.

Stage 1 First Base – This involves completion of Units 1-5 with their associated multiple choice questions. On successful completion of these 5 units, an allocated Node Leader (NL) will contact you. The NL is your training mentor and will be in charge of several trainers within a geographical location. This person has a lot of experience in rehabilitation for SCI. It is their job to advise you on the next stages of the assessment program. They will give their conservative opinions, with the trainer taking responsibility of providing the physical activity program on completion of the educational program.

Stage 2 Second Base – Second base can only be commenced after successful completion of First Base. During second base the trainer completes Units 6-10 in consultation with their Node Leader. These are the real nuts and bolts Units of the program and require a high level of involvement from trainers. MCQs are to be completed for Units 8 & 9 in addition to important assignments for Units 6 and 7. These assignments establish that your gym has the capability for wheelchair access. Next, you will record the safety and emergency responses for your gym. That is, complete the document(s) for emergency contacts etc. that are applicable for your specific

gymnasium or workplace. Unit 10 covers the process involved in appropriate goal setting for SCI participants. There is no assessment for this unit however the final page includes links to relevant assignment templates that you will need for the physical activity programme submissions during the next stage.

Stage 3 Third Base – On successful completion of second base, each trainer is teamed with a SCI participant from the community (to form a DYAD). If you have someone in mind, that would be a great help, let your NL know. If we cannot match up a partner with you then the program stops; obviously, we want to avoid this eventuality! After initial introductions between trainer and trainee, your dyad should arrange a meeting to discuss and set out specific program goals. Based on these goals, the trainer will design a set of progressive exercises that target components of a functional goal. You will need to download an assignment template from Unit 10 and insert pictures and instructions to describe each exercise; a list of <10 exercises for each specific goal component. Images for selected exercises can be sourced from various T3 SCI documents presented throughout Unit 9; simply cut the image from the word document and paste into your renamed template! You will send these to your NL who will advise of their suitability and allow you to proceed when any issues are satisfactorily amended.

Stage 4 Home Base– The 8-12 week physical activity program is commenced at reaching home base. The program running time will involve ongoing monitoring and re-evaluation of goals as you would typically undertake in your work practise. At the end of the physical activity program, you will complete final goal evaluations and research questionnaires, in addition to giving feedback to your NL.

On final completion of the T3 SCI program, you will receive certificated acknowledgement of achieving success in T3 SCI Level 1. (We are currently examining whether we can link this work with recognition as a Fitness Trainer's certificate training program, but this is not available at the moment).

Individuals may undertake multiple training options for different clients. Individual trainers, on successful completion of multiple and varied SCI clients, will have the potential to be upgraded to the level of Node Leader.

Good luck with your efforts but importantly, enjoy the learning process along the way.

2. Goal Setting is Key

An important aspect for success in this program is appropriate goal setting and ongoing evaluation. Key to getting this part right is a solid understanding of the difference between the terms 'impairment' and the impact of the impairment on the ability of the individual to perform an activity and then how this impacts on their participation. In recent years the terms 'disability' and 'handicap' have been replaced by 'limited activity' and 'restricted participation', respectively.

Impairment is defined by the World Health Organisation (WHO) as "a loss or abnormality of bodily function, which may be a physiological, psychological or anatomical change in a body part or organ system; an impairment is a condition". An example might be weak latisimus dorsi or scapula depressor muscles.

An impairment then can lead to a **limitation of activity** – WHO says "a restriction or lack of ability to perform an activity in a normal manner, which results from an impairment". This limited activity can lead to **limited participation**. This reflects an emphasis is on the practical problems faced in the performance of personal, social or occupational activities.

So here is an example: The person has weak triceps brachii muscles (the muscles that extend the elbow) - this is an impairment. This impairment means that they cannot lift their body up from the wheelchair - this is a loss of activity. This activity loss is important because individuals with SCI need to regularly change their sitting posture to relieve pressure on their skin.

So you can see that, this person's impairment results in a loss of activity that results in limited participation. Your primary focus for goal setting will be to ask what the client wants to achieve. A good goal focusses on something that improves an activity or participation. Most people working in gyms focus on the specific impairments (i.e. stronger biceps). To allow both aspects to be covered we suggest that you select a goal (i.e. the ability to transfer or the ability to attend a 4hr football game) and then break it

down to some specific aspects related to an impairment. For example, triceps strength and / or sitting balance.

The method to do this is part of their T3 SCI program. The trainers will break down a specific goal into components that can then be specifically trained to improve the capacity of the individual or address a specific impairment, like triceps weakness and or poor sitting balance. The outcome of the training program is to assess if the goal has been achieved as much as any change in the targeted impairment.

The goal setting and evaluation process will follow a six-step process as outlined in Figure 1.2 below.

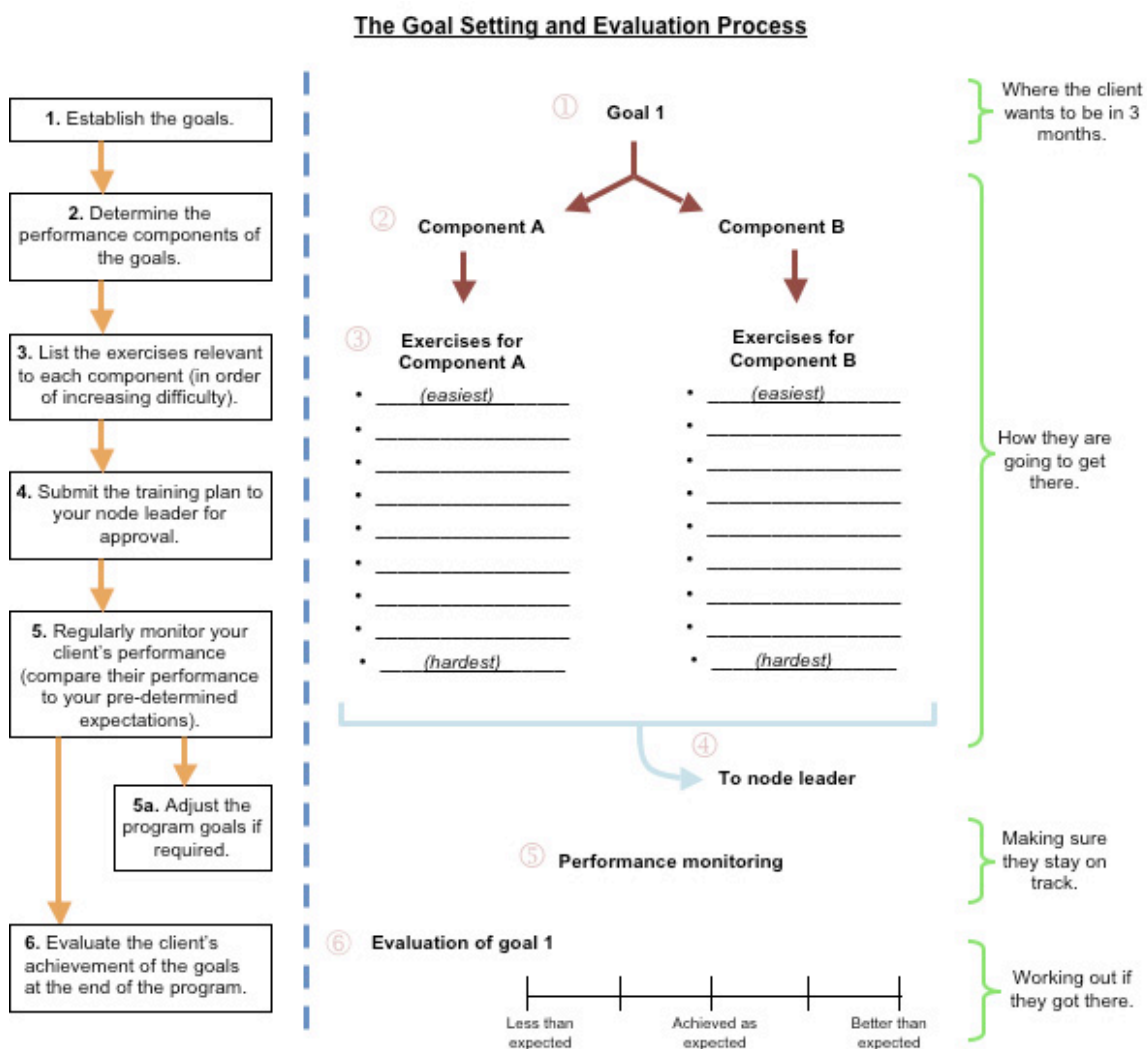


Figure 1.2. Schematic representation of the goal setting and evaluation process

3. Assignments ... the fun stuff

After you have finished Units 1-5 and their relevant Multiple Choice Questions (MCQs Units 2-4), you will be contacted by your allocated Node leader. Units 6-10 involve written assignments (Units 6 and 7) and MCQs (Units 8 and 9).

All written assignments are completed on word document templates that will be handed to you and that can also be downloaded from the web page; this process is quite self-explanatory as you progress through the units.

To submit your assignment (you will need to change the template name to indicate it's from you) you can send it to beatriz.itoramos@postgrad.curtin.edu.au or go to the relevant Unit web page and submit. The site asks you to upload the assignment where it will then be stored on the T3 web site. Your node leader will then be contacted via the site to alert them that your assignment is submitted. The node leader will read it and give you feedback and direction as to what to do next.

4. Help with assignments....?

Let's face it, you are probably working on this by yourself, at home, in your spare time! As such, you may not have a clue how to make a start on the assignments. Don't worry, it's not all bad news.

Firstly, on some of the assignments we have 'Show Case' versions for you to refer to. These are assignments that have been submitted by trainers and represent exemplars for the requirements of T3 SCI. You can use these to inform your own work in developing your physical activity program.

Also really important is that you respect the concept of the T3 organisation and that you do not use these exercise sheets or program for other purposes, they are specific to this population and program.

We will be relying on people to respect copyright.

If you upload photos and pictures in your exercise templates it is really important to understand that you cannot use images of people who have not provided consent to have their photos taken and uploaded for public consumption. Secondly, do not steal images off the web without asking permission.

One of the better FREE exercise image database can be found on our web page in Unit 8 (page 1): <http://curtintrainthetrainer.cloudapp.net/> . Have a look at this for exercise ideas.

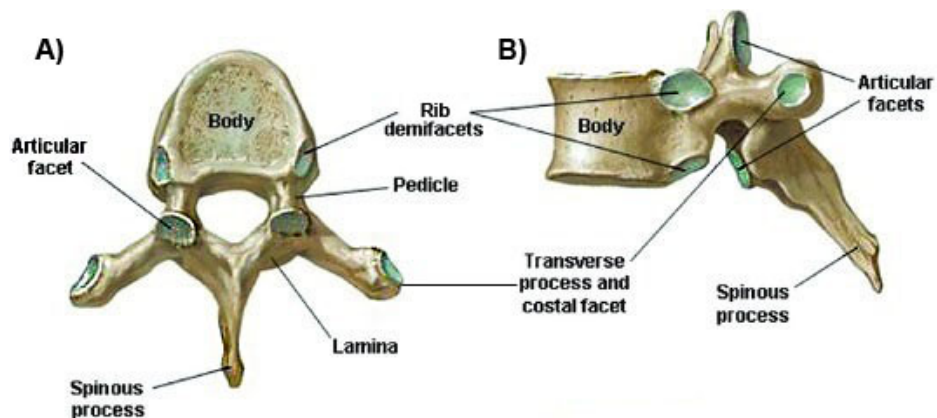
Additionally, you will find several exercise images in our own database that can be used to complete your assignments and provide handouts to your participants.

UNIT 2 - Anatomy of the spine and nervous system

Spinal Column

The spinal/vertebral column is comprised of bones (vertebrae), intervertebral discs, ligaments, muscles, and tendons. There are:

- 33 vertebrae that assist in providing structural support to hold us upright;
- 24 intervertebral discs, acting as shock absorbers to dissipate forces;
- Ligaments, which attach bone to bone and contribute to stability; and
- Muscles, which provide further stability and primarily produce movement.

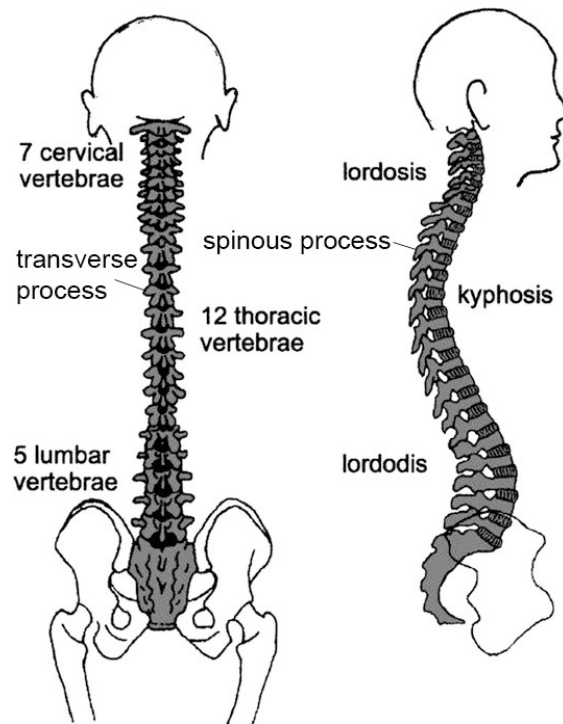


The T6 vertebra. A. viewed from above and B. laterally.

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The spine is arranged into 4 main regions, descending from the head (top) down:

- Seven Cervical vertebrae
- Twelve thoracic vertebrae
- Five lumbar vertebrae
- Five sacral and four coccygeal vertebrae.



Schematic representation of the regions of the spinal column.

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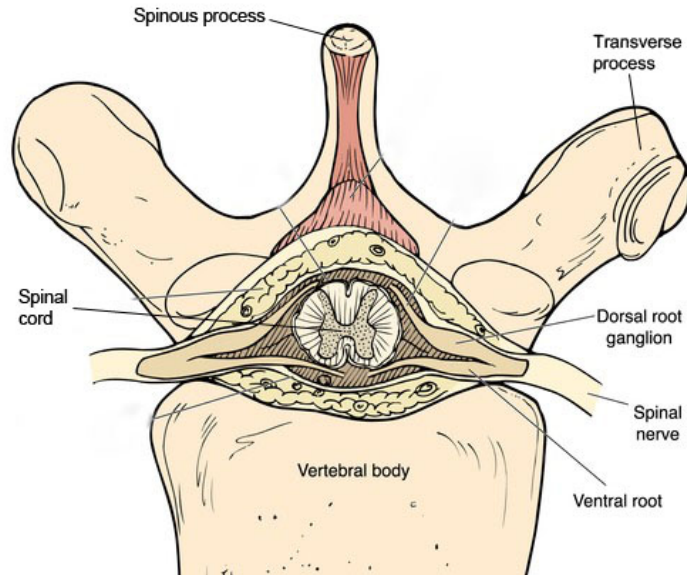
By adulthood, the sacral and coccygeal vertebrae have fused.

A spinal motion segment comprises two adjacent vertebrae, their intervening intervertebral disc, associated ligaments, tendons and muscles.

The purposes of the spinal column are:

1. To provide structural support to hold the body upright
2. To house and protect the spinal cord and exiting nerve roots

3. To provide the basis for spine movement



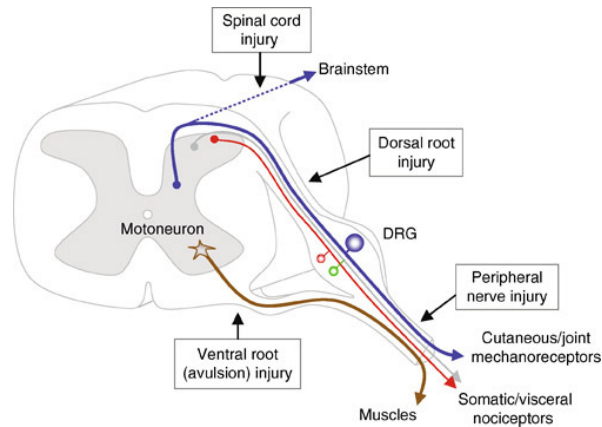
Cross-section of the spinal column

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Spinal Cord

The spinal cord is a bundle of nerves connecting the brain to all the parts of the body. Beginning at the base of the brain, the spinal cord traverses the inner part of the vertebral column (central canal), through the cervical and thoracic regions to terminate at the level of the first and second lumbar vertebrae, where it becomes the cauda equina. This is a collection of elongated spinal nerves with the appearance of a horse's tail.

Each motion segment is associated with a pair of spinal nerves, which have both sensory (sensation) and motor (muscle action) fibres. Spinal nerves leave the spinal cord in the central canal, and exit the spinal column through intervertebral foramen that are bordered by two adjacent vertebrae.

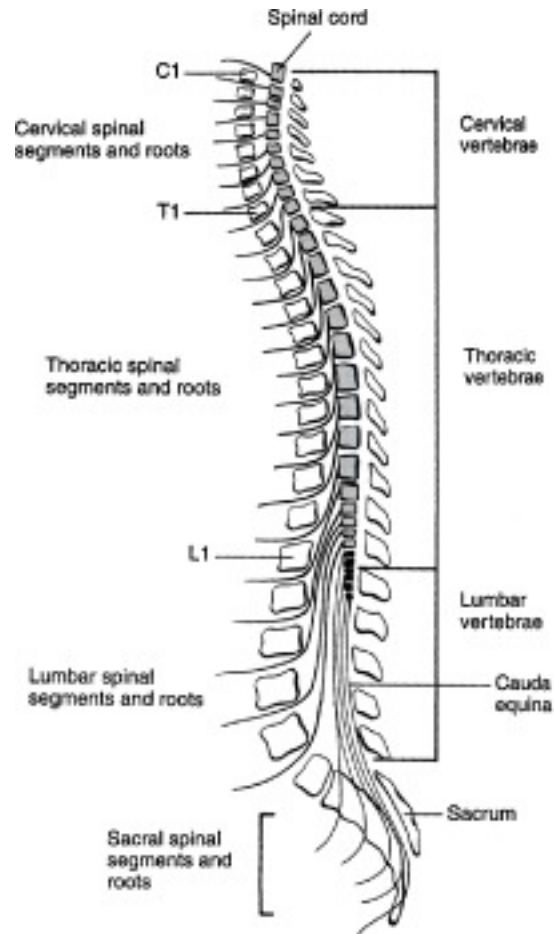


The axons of sensory (afferent) neurons (in blue) bifurcate: one branch travels to peripheral sensory organs; the other projects via dorsal roots to the spinal cord, detecting temperature or noxious (painful) stimuli (in red), and proprioception and mechanoreception (in blue). The afferent neurons are responsible for transmitting information (e.g. pain) from the periphery to the CNS. Motor (efferent) neurons are situated in the ventral spinal cord and brainstem (in brown). Spinal motor axons innervate muscle fibres in the periphery.

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There are 30 spinal nerves: 8 cervical, 12 thoracic, 5 lumbar and 5 sacral. They are named with a letter and number according to where they exit the spinal column. In the cervical region, the nerves are named with reference to the vertebra beneath the nerve (e.g. cervical nerve C2 emerges above the second cervical vertebra). This accounts for there being 8 cervical nerves despite only 7 cervical vertebrae. Spinal nerve C8 exits between the 7th cervical vertebrae and the 1st thoracic.

After this, the spinal nerves are named after the vertebra above the nerve (e.g. spinal nerve T1 emerges beneath the first thoracic vertebra).

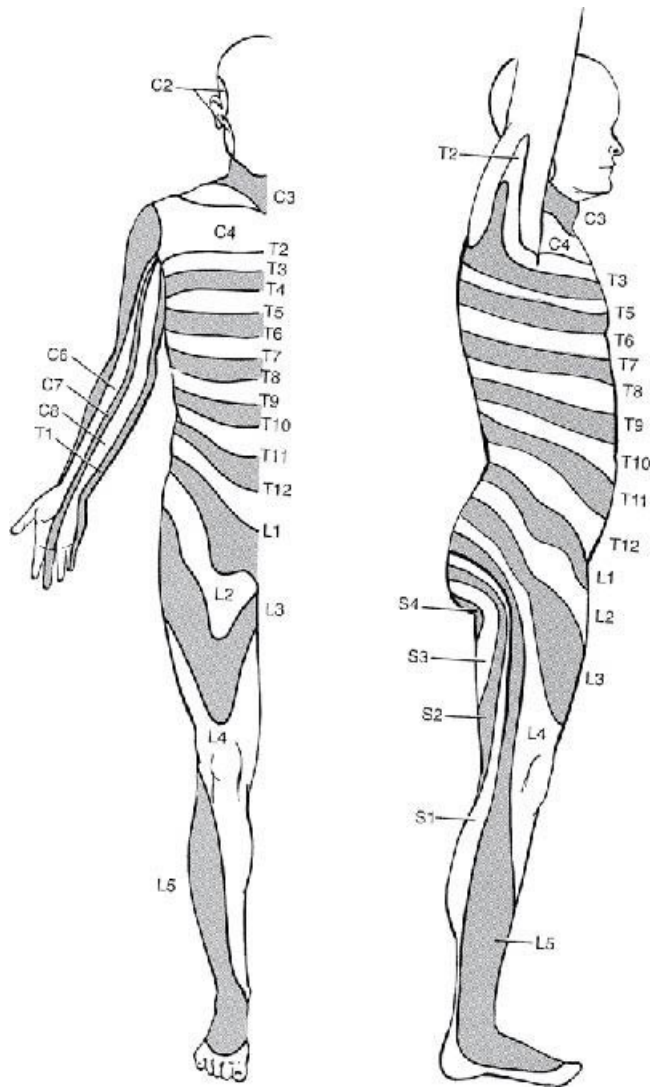


Spinal Cord. The organisation of the spinal cord into cervical, thoracic, lumbar, and sacral segments.

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Each spinal nerve is responsible for nerve supply (innervation) to a certain area of the body. The muscles that each specific nerve innervates are referred to as the myotome for that nerve, and the area of skin it innervates, is called its dermatome.

It is important to understand the area of innervation of each spinal nerve, as it will give an indication of how an injury to a specific level of the spinal cord, will affect the function of the individual. For example, a spinal cord injury (SCI) at the C5 level will affect the parts of the body innervated by spinal nerves below C5; a SCI at T6 will affect body parts innervated below the 6th thoracic level.



Dermatomes. A dermatome is the area of skin supplied by the peripheral processes from a single dorsal root ganglion.

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Nervous System

Central Nervous System

The central nervous system (CNS) comprises the brain and spinal cord, and is primarily concerned with processing the body's information. The CNS collects and integrates sensory information from the peripheral nervous system to relay information

about sensation. The CNS also sends motor commands to the peripheral nervous system to coordinate muscle action and movement.

Peripheral Nervous System

The peripheral nervous system (PNS) refers to the nerve structures beyond the brain and spinal cord. The PNS is considered to begin from the inside of the intervertebral foramen, including the nerve root and its associated nerve. The PNS relays sensory information **to** the CNS, and motor information **from** the CNS to peripheral organs. This is achieved through bundles of nerve fibres, simply known as nerves.

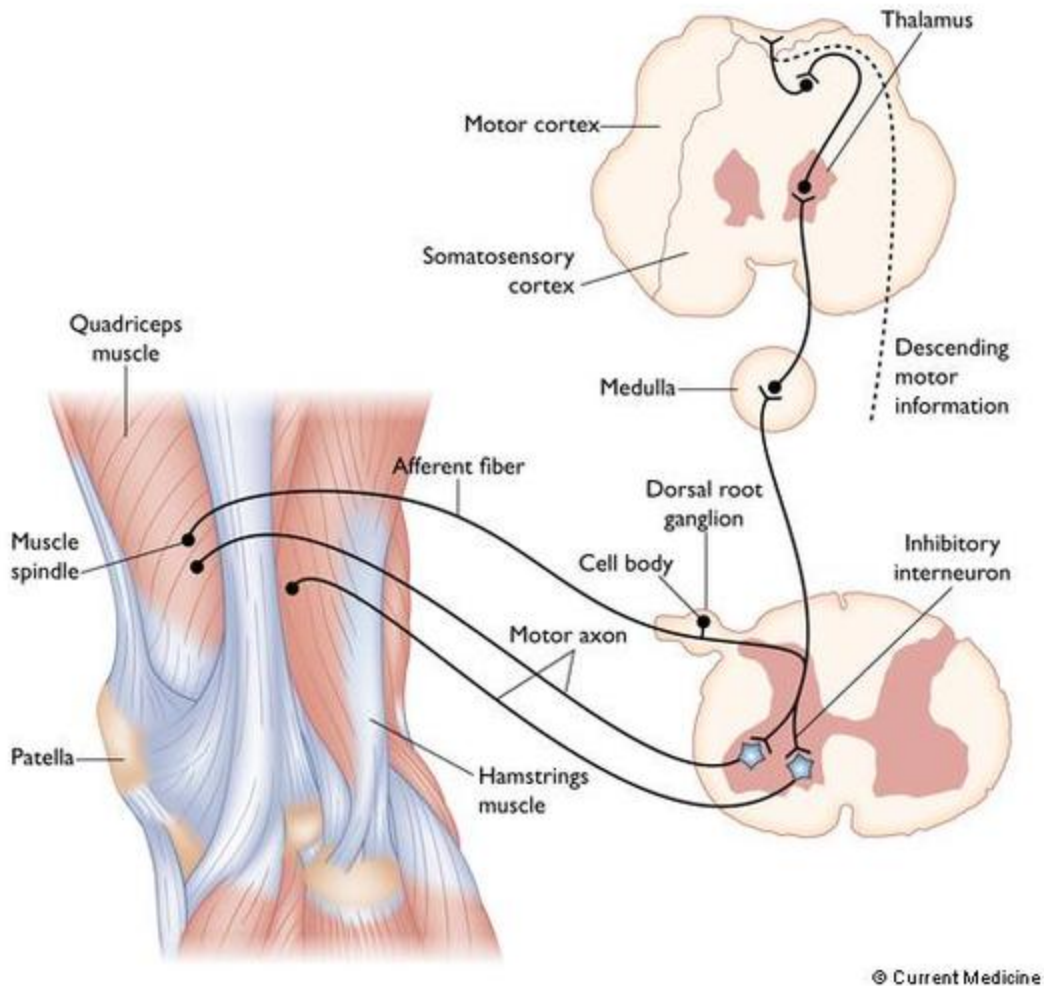
The CNS and PNS neural pathways are further divided depending on their function. **Afferent** pathways are the sensory nerves carrying messages from the **body to the brain**. These messages are about the environment and the experiences, position and health of the limbs and internal organs. **Efferent** pathways are the motor nerves carrying messages from the **brain to the body**. These messages act to execute movements and effect actions. The efferent division is further divided into the somatic and autonomic nervous systems, which depend on the target organs for the motor commands.

Somatic Nervous System

The somatic nervous system (SNS) controls skeletal muscle contractions and gathers external sensory information (e.g. the senses of skin, sight and hearing).

- **Voluntary** actions are deliberate and under conscious control.
- **Involuntary** contractions are automatic responses (reflex) and controlled at the subconscious level.
- **Reflexes** create rapid responses to a sensory message traveling up the spinal cord, before the message is received and consciously acted upon by the brain; eg why we have automatic withdrawal from a source of pain, like heat. The reflex movement is initiated by a spinal interneuron connecting the afferent and efferent nerves, which responds to specific stimuli. Although the reflex movement is initiated in the spinal cord, once the sensory message

reaches the brain, the brain will override the initial motor message to dampen and stop the reflex action.



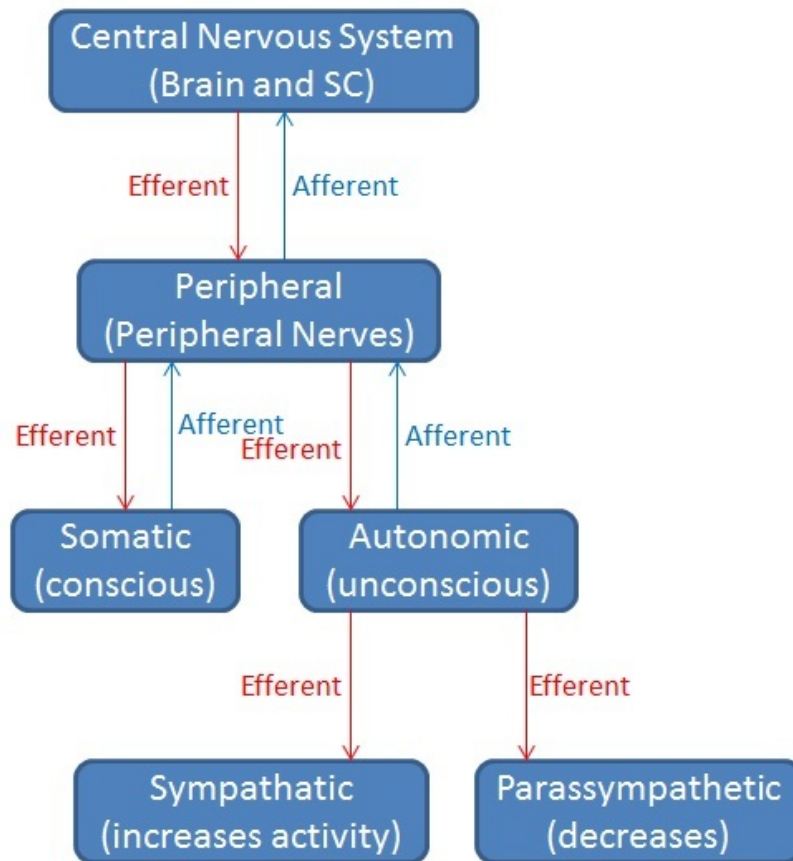
A reflex circuit in the spinal cord. The muscle stretch reflex is created by stimulation (e.g. a gentle hammer tap on the patellar tendon) of the large afferent nerves in the muscle spindle when the muscle tendon is struck. In the spinal cord, the sensory neurons act directly on motor neurons, which contract the muscle. In addition, the sensory neurons act on inhibitory interneurons to inhibit the motor neurons that would contract the opposing muscle.

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Autonomic Nervous System

The autonomic nervous system (ANS) controls automatic systems such as breathing, heartbeat, blood pressure, and temperature regulation. The afferent nerves gather internal sensory information about things like heart rate and organ health. At the subconscious level, efferent nerves regulate the smooth muscles of the gastrointestinal tract, heart and glands at the subconscious level. The efferent nerves of the ANS can be **sympathetic** or **parasympathetic** depending on their effect on the target organs.

The sympathetic division of the ANS prepares the body for fight or flight in response to danger (**increasing** heart rate, respiratory rate, temperature etc.). The parasympathetic has the opposite effect by **decreasing** the activity of these systems.



Structure of the Nervous System

Table 1.1. This table lists the key facts of the autonomic nervous system (ANS) including the function of the ANS, the complementary functions of the sympathetic nervous system and parasympathetic nervous system

1. The autonomic nervous system (ANS) is the part of the peripheral nervous system that acts as a control system.

2. The ANS controls visceral functions such as heart rate, digestion, respiration rate, salivation, perspiration, diameter of the pupils, urination, and sexual function.

3. The ANS is divided into two parts: the sympathetic nervous system (SNS) and parasympathetic nervous system (PNS).

4. Functionally, the SNS and PNS are complementary in maintaining a balance in the tonic activities of many visceral structures and organs.

5. The SNS is concerned primarily with organ responses during rage and fright, such as increase of heart rate and blood pressure.

6. The PNS is concerned primarily with conservation of energy and maintenance of organ function during periods of minimal activity such as decrease of heart rate and blood pressure.

Injury and Repair of the Nervous System

The blood brain barrier

The blood brain barrier (BBB) is the membrane surrounding the central nervous system (CNS) to separate the normal circulating blood and the cerebrospinal fluid. It is a very fine collection of cells that act like a filter to keep out bacteria and infections. The protection that the BBB provides means that the immunological response of the CNS is different to that of the PNS.

Importantly, the potential for repair of damaged neural pathways is different between the CNS and the peripheral nerves lying outside the BBB. The body has a system of repair for peripheral nerve injuries but neural repair within the BBB is less

effective. Provided the ends of the injured peripheral nerve are in close proximity, peripheral nerve injuries can heal over time. In contrast, a CNS injury does not repair to the same extent, leaving the lasting damage associated with SCI.

Injury

When a peripheral nerve is damaged and electrical impulses are not able to cross the injured site, the information transmitting through the nerve is impaired.

If the nerve is a sensory nerve (afferent) then the individual may have altered sensation. Anaesthesia is the term used to describe a complete loss of signal transmission i.e. total loss of sensation. Paraesthesia refers to a partial loss of sensation.

If the affected nerve is a motor nerve (efferent), then messages to the person's muscle fibres can be impaired. Paralysis occurs with a total motor loss. Partial sparing, where some muscle fibres continue to be activated, is termed paresis.

It should be emphasised that damage to the peripheral nerves is different to damage to the CNS: spinal cord or the brain.

When the spinal cord is injured there can be a mix of sensory and motor impairments that vary according to the extent of the injury. This topic is discussed in Unit 2.

When the brain is injured (eg in a head injury or stroke), there are often complex perceptual problems that impact on cognitive function, perception, planning and communication. This is in addition to impairments in sensation and motor control.

Unless there has been an additional head injury, individuals with SCI or a peripheral nerve injury will not have problems of cognition.

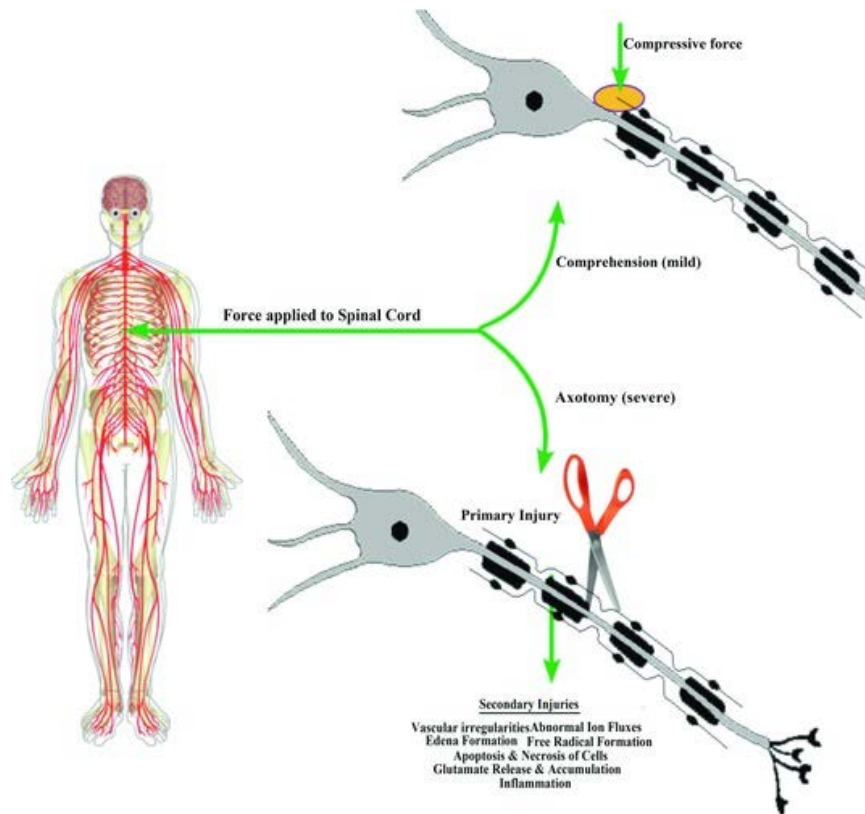
Unit 3 - Spinal Cord Injury

Causes and Effects of Spinal Cord Injury

In Australia, more than 10,000 people are living with spinal cord injury (SCI). The majority are males (80%) with the highest incidence in those younger than 25 years. The annual national cost of SCI is estimated at \$2 billion, which represents a sizeable economic burden.

The main causes of SCI are: transport accidents (49%), falls (29%), sporting accidents (16%), dive/swim accidents (9%), and others such as medical complications/self-inflicted injury (9%).

Spinal cord injury (SCI) disrupts communication between the brain and the body, not by affecting the brain or peripheral system's individual ability to send and receive messages, but rather to transmit or relay the messages between themselves. As an analogy, it is like a severed telephone line, where the receivers/ handsets at either end of the line are functioning, but the communication line between them is broken - nothing that is sent from either end is received at the other.



Spinal cord injury occurs when significant amounts of force are applied to the spinal cord. This force can lead to two initially indistinguishable outcomes: axotomy or compression of neurons or spinal fluid.

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Tetraplegia (also known as quadriplegia) represents disturbance of the upper limbs, trunk and lower limbs secondary to SCI affecting the cervical region.

Paraplegia affects the trunk and/or lower limbs only and results from SCI to the thoracic, lumbar or sacral regions.

If motor messages sent from the brain cannot continue past the level of the lesion, movements will not be executed below the level of the injury; paralysis and anaesthesia occur.

However, as reflexes are a result of motor-sensory connections in the spinal cord, reflex circuits below the injury level remain functional. But, the brain cannot react to

modify the reflex motor activity because the initial sensory message cannot reach the brain.

This results in muscular **spasm** or **spasticity**. For more information on spasticity check out this link: <http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.4453419/k.3757/Spasticity.htm>

Injury Classification

Spinal cord injury is classified according to where in the spinal cord the injury has occurred (Hefferan et al.), and the extent of changes to sensory and motor function (completeness).

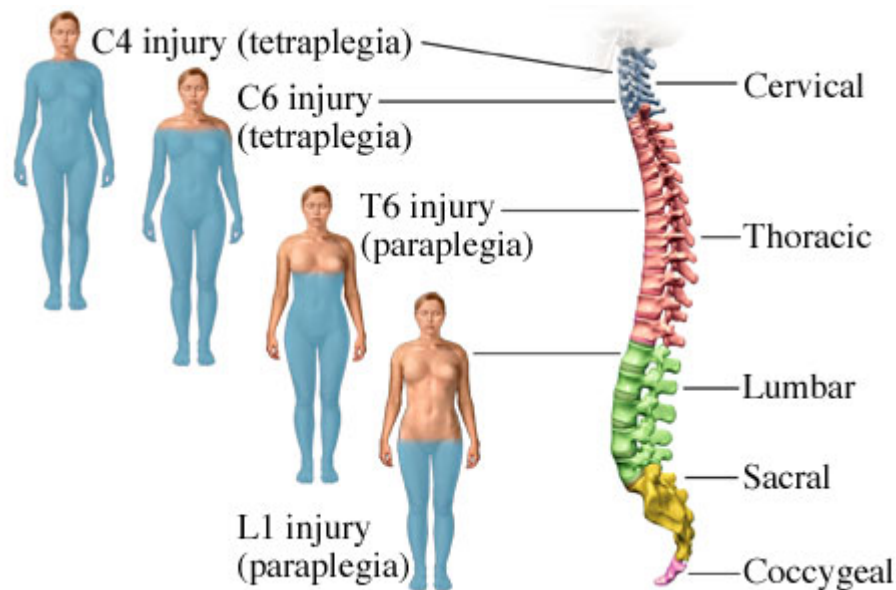
Level of injury

The level of SCI is reported in two ways: orthopaedic and neurological.

Orthopaedic refers to the level/s of the vertebra/e that suffered the most damage and may be one or multiple.

The neurological level of SCI refers to the lowest full- function neural level. The neurological level gives an indication of the motor and sensory function of the injury. For example, a C5 neurological SCI means the individual will have full function of sensation and motor function of the structures supplied by the spinal cord levels up and inclusive of C5 nerves (eg. deltoid and biceps) but, they have impaired or absent function of structures supplied by C6 and below (eg. triceps and wrist extensors/flexors).

In terms of orthopaedic level, they may have damage to C4-7, but given neurological impairment below C5, a C5 classification is used.



Levels of spinal cord injury.

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Complete/incomplete

For the purpose of this training program we will use the idea of functional completeness, as different from anatomical completeness.

A **complete** SCI means there is no sensation or movement below the level of injury, resulting in paralysis and anaesthesia.

Incomplete SCI means there is some remaining movement and/or sensation below the level of injury, but the extent of paraesthesia and paresis differs for each individual. Some people with an incomplete SCI may be able to walk.

Asia Classification

ASIA is the American Spinal Injury Association. ASIA classification is a reliable and valid clinical classification system of the neurological level of SCI. Health professionals regularly assess the ASIA classification of an individual throughout their rehabilitation. Motor and sensory functions according to innervation levels are assessed and recorded. Although there may be initial changes during the acute and sub-acute

stages post-injury, ASIA classification usually stabilizes 3 to 6 months into rehabilitation and after initial injury. This means you are unlikely to be working with anyone who is undergoing monitored ASIA classification and instead they will already have a classification. Take a close look at the ASIA classification form below and see how the level and completeness of injury is worked out.

Patient Name _____
 Examiner Name _____ Date/Time of Exam _____

ASIA **STANDARD NEUROLOGICAL CLASSIFICATION** **ISCS**
AMERICAN SPINAL INJURY ASSOCIATION **OF SPINAL CORD INJURY**

MOTOR **KEY MUSCLES** (scoring on reverse side)

	R	L	
C5	<input type="checkbox"/>	<input type="checkbox"/>	Elbow flexors
C6	<input type="checkbox"/>	<input type="checkbox"/>	Wrist extensors
C7	<input type="checkbox"/>	<input type="checkbox"/>	Elbow extensors
C8	<input type="checkbox"/>	<input type="checkbox"/>	Finger flexors (first phalanx of middle finger)
T1	<input type="checkbox"/>	<input type="checkbox"/>	Finger abductors (ring finger)
UPPER LIMB TOTAL (MAXIMUM) <input type="checkbox"/> + <input type="checkbox"/> = <input type="checkbox"/> (25) (25) (50)			

Comments: _____

SENSORY **KEY SENSORY POINTS**

		R	L	R	L
C2					
C3					
C4					
C5					
C6					
C7					
C8					
T1					
T2					
T3					
T4					
T5					
T6					
T7					
T8					
T9					
T10					
T11					
T12					
L1					
L2					
L3					
L4					
L5					
S1					
S2					
S3					
S4-S5					

0 = absent
 1 = impaired
 2 = normal
 NT = not testable

Voluntary anal contraction (Yes/No)

Any anal sensation (Yes/No)

LOWER LIMB TOTAL (MAXIMUM) + = (25) (25) (50)

TOTALS (MAXIMUM) (50) (50) (50) (50) (50) (50) →

ASIA IMPAIRMENT SCALE

NEUROLOGICAL LEVEL: The most caudal segment with normal function.

COMPLETE OR INCOMPLETE?

INCOMPLETE = Any sensory or motor function in S4-S5

ZONE OF PARTIAL PRESERVATION: Caudal extent of partially preserved segments.

SENSORY MOTOR:

SENSORY MOTOR:

Pin Prick Score (max 112)

Light Touch Score (max 112)

Key Sensory Points

REV 03/06

International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI)

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Clinical Syndromes

Clinical syndromes associated with SCI are clusters of symptoms that correlate with specific clinical presentations.

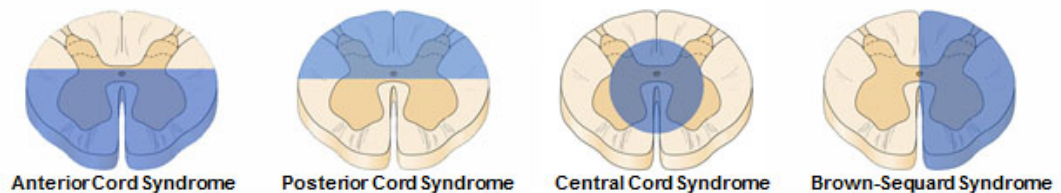
Central cord syndrome is caused by bleeding in the central aspect (gray matter) of the spinal cord in the cervical region. It is unlike other (typically traumatic) SCI, and results in greater impairment in the upper limbs than the lower limbs.

Anterior cord syndrome causes loss of movement below the level of injury as well as loss of pain and temperature sensations. As the injury is only to the anterior part of the spinal cord, some sensations such as pressure and joint position sense may remain intact.

Posterior cord syndrome causes impaired movement coordination due to loss of proprioception (sense of position), while motor function remains intact. With an injury to the posterior cord, the anterior pathways may be partially spared.

Brown-Sequard syndrome occurs when the injury is mainly to one side of the spinal cord. Movement, pressure and joint position sense are affected only on the injured side, while pain and temperature sensation are affected on the uninjured side.

Cauda equina syndrome occurs with SCI below T12. It is often caused by disc herniation in the lumbar region. There is loss of bladder and bowel control, and there may also be loss of movement and sensation in the legs. For more information follow this link <http://emedicine.medscape.com/article/791613-overview>.



Secondary effects of SCI

Spinal cord injury has a dramatic impact on all systems of the body.

The following are the main physical changes relevant for anyone undertaking physical training of individuals with SCI. The list is not exhaustive and you are encouraged to read more widely to better appreciate the depth of effects.

Changes to thermoregulation

Humans lower their body temperature predominantly through the automatic responses of perspiration (sweat) and vasodilation (opening) of blood vessels close to the skin.

The spinal levels that control this mechanism centre at T4-6.

Therefore, individuals with SCI to the cervical or high thoracic levels are unable to maintain a comfortable body temperature via usual mechanisms. Instead, to allow thermoregulation they need to alter their external environment (e.g. with clothing/heaters/air conditioners).

In the exercise setting, priority should be paid to the inability of cervical and high thoracic SCI cases who are more susceptible to heat exhaustion as a consequence of their inability to automatically thermoregulate.

The following link presents a video showing various methods a C6 tetraplegic guy uses to moderate his temperature

<http://www.youtube.com/watch?v=w3UkVWDdKtA&feature=related>

Changes to the respiratory system

SCI occurring above and inclusive of C4 will affect innervation and function of the diaphragm, the primary muscle of respiration. Like Christopher Reeves, individuals without a functioning diaphragm will use a tracheostomy (an artificial airway placed directly in the neck to allow air exchange between the trachea and the environment) and ventilator to breathe.



Christopher Reeves required breathing apparatus after his injury in 1995.

The diaphragm is assisted by other muscles: neck muscles, intercostals (muscles between the ribs), pectorals (anterior chest), scapulae muscles (posterior chest) and the abdominals. Collectively, these muscles are known as the accessory muscles of respiration and are used to expand the ribcage or forcefully expel air from the lungs. Trunk muscle groups are all affected by injury above T12.

With impaired accessory muscle function it is difficult for the individual to take a deep breath or perform an effective cough. This can lead to increased secretions in the lungs resulting in partial lung collapse or chest infections. Tetraplegics and high thoracic paraplegics have particular difficulty and require assistance to cough (elaborated in Unit x).

Respiratory muscle paralysis can cause a significant decrease in the SCI individual's lung function (expiration and inspiration). Vital capacity (VC) is the maximum amount of air an individual can expel from their lungs following a maximal inspiration. After SCI, VC of tetraplegics is approximately 58% of normal, while VC of paraplegics is approximately 73% of normal.

Individuals with SCI have more risk of respiratory muscle fatigue, which may result in an inability to increase lung volume when there is an increased demand for oxygen, such as with exercise. Breathlessness and de-oxygenation (inadequate blood oxygen levels) may occur. Respiratory capacity can be improved, where necessary, by using an abdominal binder during exercise.

Another practical consideration is that some individuals with relatively high SCI may speak relatively quietly. It is important to understand this is potentially a result of the lesion and not necessarily a quiet personality!

Changes to the cardiovascular system

SCI above and including T6 will result in impaired cardiac conduction and decreased ability to regulate vascular tone below the lesion.

Clinically, these cardiovascular changes can manifest as:

- Low resting systolic blood pressure (SBP, 70-90 mmHg)
- Blunted maximum heart rate of approx. 120bpm
- Decreased heart rate acceleration in response to exercise
 - **Heart rate is not a reliable measure of exercise intensity in this population**
- Cardiac conduction disorders e.g. atrial fibrillation
- Orthostatic hypotension (blood pooling in the lower limbs) as there is no active muscle pump to improve venous return in upright positions
- Deep vein thrombosis due to peripheral venous stasis. They may wear compression stockings or abdominal binders to improve venous return.
- Atherosclerosis and myocardial infarction
- Poor healing due to decreased blood flow
- Large day-to-day variations in endurance and cardiovascular reserve

Spinal cord injury below T6 will not affect cardiac conduction but will impair vascular tone below the level of the lesion. Cardiogenic reflexes and cardiovascular response to exercise will mirror that of able-bodied persons, however low blood pressure and orthostatic intolerance will be relevant.

Changes to metabolism

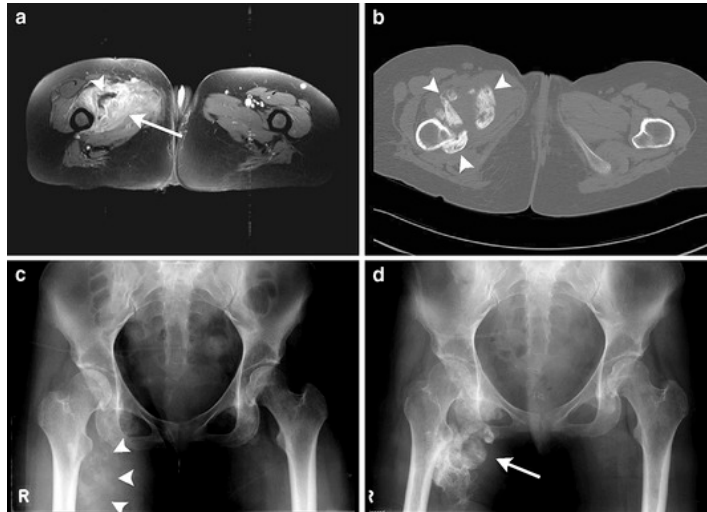
The resting metabolic rate of an individual with SCI is 10-30% lower than in an able-bodied comparison. Being in a wheelchair results in a more sedentary lifestyle and often results in weight gain. Body composition changes as muscles atrophy and the percentage of body fat increases as the mass of lean muscle decreases.

Body mass index (BMI) does not consider metabolic disturbance in SCI and is therefore not an appropriate appraisal measure. Similarly, skin fold measures are less applicable in this population.

The lipid (fat) profile of individuals with SCI also changes, with an increase in total cholesterol and a decrease in high-density lipoprotein (HDL, good cholesterol). This increases cardiovascular disease risk, and like the wider population, is one of the major causes of mortality in SCI. Many individuals also develop insulin resistance, increasing their risk of diabetes and diabetes-related illnesses.

Changes to bone structure

Following SCI there is a rapid demineralisation of bone in the entire skeleton (except for the skull). Demineralisation particularly occurs in the femurs, tibiae and pelvis. Approximately 4 months after injury, the arms and trunk begin to improve bone density with increasing wheelchair mobility and participation in physical activities. However, bone density in the lower body continues to decline. By 10 years after initial injury, 50% of the bone in the pelvis and lower limbs is demineralised, or osteoporotic. Bones then become vulnerable to fractures even in relatively minor trauma. Individuals with complete SCI have 10 times the fracture rate in lower extremities than those with incomplete injuries.



Heterotopic ossification.

Another skeletal complication following SCI is **heterotopic ossification**. This is the formation of bone within soft tissue and outside of the normal skeleton. It usually occurs at major joints like the hips, shoulders and knees. Heterotopic ossification has the potential to cause joint fusion, which may affect range of motion and function. It usually occurs in the initial months after SCI, and if functional capacity is threatened, can be treated by surgical excision of the extra bone.

Changes to skeletal muscle and connective tissue

Structural and contractile changes can be seen in skeletal muscles in less than one month after SCI. Denervated muscles below the injury site have smaller muscle fibres and decreased contractile force (muscle atrophy); they have increased fat content and are more readily fatigued.

Muscle imbalances on opposing sides of a joint can lead to shortening of connective tissue fibres (contractures), resulting in reduced range of motion (ROM) and potentially significant musculoskeletal pain.

Imbalances may be due to spasm (hypertonic muscle contraction) or uneven muscle innervation on opposing sides of a joint. If the joint is allowed to rest in a fixed position, the connective and contractile tissue on one side of the joint will lengthen, while tissues on the other side shorten. Additionally, muscles will be unevenly activated. Passive ROM exercises are used to maintain joint range. Stretching exercises should be carefully considered in the presence of sensation changes. Muscle balance

surrounding the joint complex is an important consideration when designing an exercise program for an individual with SCI.

Changes to stability, balance and posture

Most individuals with SCI have some degree of impaired trunk control; this affects stability given there is limited muscular capacity for small adjustments and maintaining balance. Poor trunk balance and postural stability presents problems for reaching, lifting, and weight-shifting or transferring tasks. External supports like a chest strap may be of benefit in supporting the upper body during activity. Trainers need to consider the quality of movement throughout skill acquisition and understand that for 95% with SCI, “core stability” exercises are entirely inappropriate.

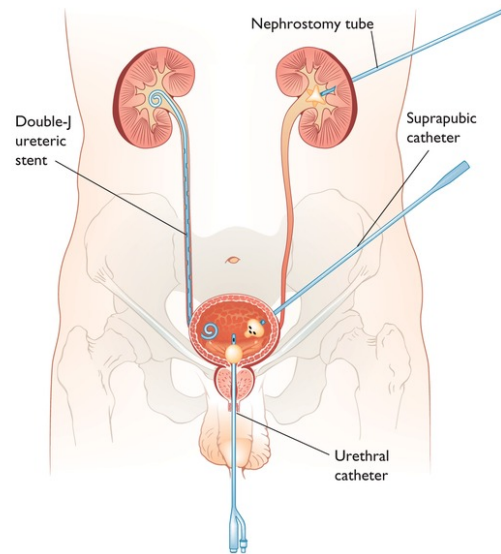
Trunk weakness generally leads to progressively poor wheelchair posture. This in turn impairs diaphragmatic breathing (where relevant) and the ability to use the upper limbs away from the body. Poor posture may also result in kyphosis or scoliosis and may lead to chronic pain and fatigue. This is worse in deconditioned individuals and places them at more risk of skin complications like pressure sores.

Changes to bladder and bowel function

Bladder and bowel control are regulated by nerves arising from the lowest sacral segments. Thus, the majority of individuals with SCI will have impaired bladder and bowel function.

Bladder management requires use of a catheter inserted into the urethra to empty the bladder. The catheter may be indwelling (connected to the bladder at all times) or intermittent (used at timed intervals when the bladder is full and requires emptying). An indwelling catheter will be connected to a bag strapped to the leg to collect urine; it will generally be concealed under clothing. The tubing between the catheter and collection bag must be monitored for kinks or twists. Individuals using intermittent catheters will require access to toilet facilities to empty their bladder.

Bowel management is typically performed at the same time every day or second day to train the body to defecate at predictable times. Some individuals may have a stoma bag attached to the abdomen for collection of faeces directly from the intestine.



Sites and routes of urinary catheters. Catheters and stents are used to drain the bladder and kidneys. Catheters may be inserted into the bladder through the urethra or a percutaneous suprapubic route. The kidney can be drained with a percutaneous nephrostomy catheter or with a ureteric stent into the bladder.

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Treatment for SCI

Individuals with a SCI may be hospitalised for 5-8 months following their injury. The exact treatment depends on the severity and type of injury, other injuries that occurred at the time of injury, as well as any other pre-existing health conditions.

Acute stage

Initially, the patient is admitted to an emergency hospital centre for treatment and stabilisation of injuries. Monitoring of breathing, cardiac function and blood pressure during spinal shock is key. The spine is stabilised as soon as possible, and may require insertion of rods, halo traction, excision of bone fragments and/or fitting of a back brace.

Rehabilitation

Once stabilised, the patient is transferred to a Spinal Unit specialising in rehabilitation of SCI. A team of health professionals including doctors, nurses, occupational therapists, physiotherapists, psychologists and social workers assist the patient to set and achieve goals for their recovery. Once the patient has achieved their goals, and has arranged suitable accommodation and care arrangements (if required) they will be discharged.

After Discharge from Hospital

The general practitioner becomes the primary health care provider. The patient will attend the Spinal Unit annually for urology tests and pressure management. If there are any problems or queries the individual should contact their local Spinal Unit or Spinal Health Nurse.

Life Expectancy

Advances in management and monitoring of renal function have greatly improved the life expectancy of individuals with SCI. Those who survive the first year after injury may now expect to have close to normal life expectancy.

Septicaemia and pneumonia are the main causes of morbidity in SCI. Conditions associated with sedentary lifestyles and ageing, like atherosclerosis, obesity, insulin resistance and cancer, are becoming a more prominent issue. Like for all Western societies, increasing levels of physical activity is fundamentally important for individuals with SCI and should be the underlying principle to promoting healthy lifestyles.

Possible functional expectations following SCI

The extent of impairment following a spinal cord injury is dependent upon many factors such as health status before injury, age, extent of other injuries, effective rehabilitation, access to quality health care, financial status and availability of support networks of friends and family. The table below is a guideline to expected function for

extent of impairment and level of independence one year after a spinal cord injury. These outcomes may be useful for setting short and long term goals, but are based on averages and are not a guarantee that an individual will achieve these levels of independence.

Level of SCI	Additional muscle innervation	Probable independence with	Probable assistance required for
C1-4	Head and neck control	Can speak and swallow	No muscles of respiration, breathing (requires ventilator)
C5	Deltoid (raise arm), biceps brachii, brachialis, brachioradialis (bend elbow), upper trapezius (shoulder shrug)	Possible use of chin-controlled wheelchair	Bed mobility, bladder and bowel care, pressure care, personal grooming, eating and transfers
C6-C7	Triceps brachii (elbow extension), wrist flexors, some finger flexors and extensors, thumb movement	Grooming, bed mobility, bladder and bowel care, pressure care, slide board transfers	Bathing
T1	Full hand and upper limb	All self-care, mobility	
T2-T6	Some intercostals, long back extensors	Trunk stability	
T12	Abdominal muscles thoracic musculature, trunk rotation	Possible ambulation with knee ankle foot orthoses (KAFO) and crutches	
L4	Quadratus lumborum (side flexion), lower erector spinae, hip flexors and quadriceps	Ambulation with bilateral ankle foot orthoses (AFO) and crutches	

Unit 4 – Clinical and Medical Considerations

Common secondary conditions of SCI

There are several clinical conditions that exist as a secondary consequence of SCI.

Spasticity

Spasm is a protective reflex that usually occurs when the body detects a noxious stimulus. Spasm can indicate something is wrong, like an overfull bladder. It may result from increased neural system activity that may happen during exercise. Uncontrolled spasm can be painful and may interfere with daily functional activities. Antispasmodic medications like baclofen may be prescribed by their doctor. Take a look at the video clip showing several examples of people with spasticity both before and after baclofen pump insertion; the second clip is of a T10 paraplegic.

<http://www.youtube.com/watch?v=ivP41aMxMr8>

Some degree of muscular spasm, however, can be useful to promote circulation, maintain tone of denervated muscles, maintain bone density, and assist with weight bearing during transfers on and off equipment.

If an individual suffers uncontrollable spasm, activity should be immediately ceased. If the spasm was in response to an exercise, the individual may try the exercise again at a later date but should begin at a lower intensity or load.

Skin injury

Following SCI the skin becomes weaker, less elastic and less resistant to injury. Coupled with impaired position sensation, the skin becomes more vulnerable. The most common injuries to the skin in the SCI population are burns (friction and heat) and pressure sores.

Pressure sores are caused by prolonged pressure to the skin, which impairs blood flow, starving the skin of blood and nutrients, resulting in tissue breakdown.

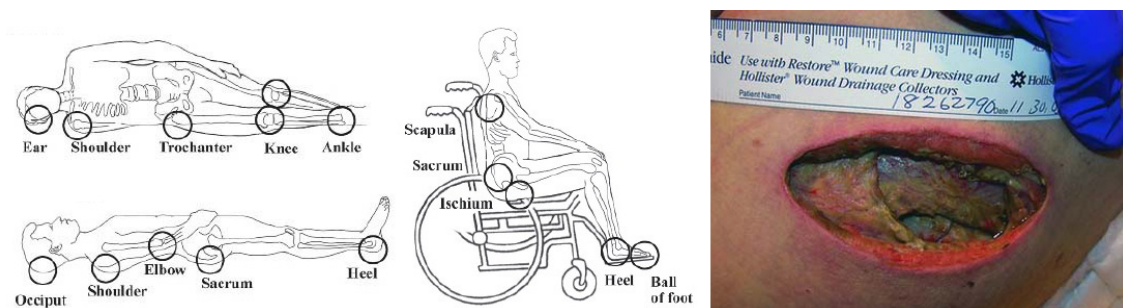
Pressure sores usually form where bony areas are close to the surface of the skin such as the ischium, coccyx and heels (see Figure 3.1). Poor skin integrity, compromised circulation, muscle atrophy, shearing of the skin (e.g. with transfers on/off equipment) and excessive moisture (e.g. sweat/bladder problems) increase the risk of skin breakdown. Poor circulation, inadequate nutrition and metabolic disorders will delay the healing process once skin damage has occurred. An example of a pressure ulcer is illustrated in Figure 3.2.

Given their extensive hospital-based rehabilitation in Australia, all individuals with SCI should be aware of the high risk of pressure sores and should implement regular pressure prevention strategies e.g. special wheelchair cushions, two-hourly position changes (even at night), lifting out of the chair every 20 minutes. As a result, shifting body weight is an important element of SCI training program, as it is a critical functional ability that provides significant health benefits.

Every person with a SCI will have a wheelchair seat cushion that has been modified for them to account for their specific anatomical needs. The cushion is suited to them alone and should not be used by anyone else.

Take a look at this guy's website and particularly the health section. He has a high level SCI and uses an electric wheelchair for mobility. He outlines several considerations regarding maintaining good skin integrity, which you will realise is of high importance in maintaining a healthy lifestyle.

<http://www.marksterle.com/health.html>.



Common pressure sore sites and a pressure ulcer debrided to underlying muscle tissue.

Autonomic dysreflexia

Autonomic dysreflexia (AD) is a serious complication associated with SCI above and including T6.

When the body detects a noxious stimulus, nerve impulses are sent to alert the brain. As they transit through the spinal cord, these messages activate the sympathetic nervous system to initiate an autonomic response. Normally, the original nerve impulses arrive at the brain so action can be taken to effectively neutralize the stimulus and stop the autonomic system action. However, in SCI, the alert message is sent but prevented from reaching the brain by the spinal cord lesion. The ANS response is still initiated below the level of the lesion, leading to reflex spasms, blood vessel constriction and a rise in blood pressure. The brain detects the blood pressure rise (although unaware of the original noxious stimulus) and sends messages to slow down the heart rate and dilate the blood vessels. These messages are unable to cross the lesion and only affect vessels above the lesion. Therefore, blood pressure will not be effectively regulated until the original stimulus is removed.

AD can be dangerous and potentially fatal as the individual's blood pressure can increase to the extent that they suffer a stroke.

For more information on secondary problems and conditions following SCI, follow this [link](http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.4453157/k.6464/Secondary_conditions.htm)
http://www.christopherreeve.org/site/c.mtKZKgMWKwG/b.4453157/k.6464/Secondary_conditions.htm.

Surgical Fusion and Range Limitation

Spinal fusion and fixation with internal rods are common surgical interventions following SCI. Bone and soft tissue trauma at the time of injury often involves fracture and subluxation or dislocation of the vertebrae. This leads to instability at the vertebral motion segment, which can further compromise the person's neurological recovery if not stabilised with surgical internal fixation. Examples of fixation devices are included in Figure 3.3. Surgical fixation may affect the individual's flexibility and ability to perform exercises that require range of movement through their spine. Some individuals may also have joint range limitations due to secondary complications such as contractures, heterotopic ossification or other bony injuries sustained at the time of their injury.

Pain

Pain is a common complication following SCI and may be of a neuropathic or musculoskeletal origin. Chronic pain also causes fatigue, and may lead to depression, lack of motivation, inactivity and decreased levels of independence.

Neuropathic pain is felt at or below the level of injury, and is caused by abnormal signals from damaged nerves in the area of injury. It is difficult to treat, and is usually managed with a combination of medications, physiotherapy, exercise and alternative therapies.

Musculoskeletal injury often occurs because of the increased load placed on the upper body during transfers and for mobility, particularly the shoulders. Muscle imbalance, contracture and overuse injuries in the upper limbs are especially common and may significantly decrease the independence, activity and participation of someone with SCI.

General considerations

People with spinal cord injury (SCI) may have a variety of chronic conditions. The condition's pathophysiology, medications, alterations in response to exercise and reduced physiological reserve, must all be considered when designing a physical activity program.

The primary aims of a physical activity program should be:

(Australian Human Rights Commission) Maintain the best possible health for independent living; and

(2) Facilitate the best achievable quality of life.

Before starting a physical activity program it is important to assess:

(Australian Human Rights Commission) Risk of exercise making an existing condition worse;

(2) Risk of other complications such as falls and heart problems.

Low intensity exercise is usually safe, even for those with a high risk of complications. Individuals who are not safe at this level of activity are unlikely to be living independently in the community.

Cardiac dysfunctions

Cardiovascular problems are the leading causes of morbidity and mortality in both acute and chronic stages of SCI. All participants with cardiovascular conditions such as bradycardia, atrial fibrillation, those with a cardiac pacemaker or a history of myocardial infarction or angina, should have clearance from their medical practitioner before commencing a physical activity program.

Osteoporosis

Permission to participate and details of any specific limitations to activity should be sought from their doctor for cases with diagnosed osteoporosis.

Epilepsy

Although the causes of epilepsy are often unknown, it is a common consequence of traumatic head injury and may be relevant in some SCI cases. There is a great variety of how individuals with epilepsy respond to exercise. Prior to setting their activity program, their type of seizure, medications and any precipitating factors, should all be considered in consultation with their doctor.

Stroke

A stroke (cerebrovascular accident, CVA) is caused by oxygen deprivation to the brain. Strokes are usually the consequence of an underlying vascular disorder and a client who has a previous history of stroke should have permission from their doctor before participating in a physical activity program. If dizziness, chest pain or shortness of breath occur during exercise, it is important to stop exercising and seek medical approval before returning.

Medication

The majority of people with SCI will be taking medication of some sort, most for bladder management, pain or spasticity. Some of these medications may have an effect on cardiovascular function at rest and/or during exercise. Common drugs and their precautions for exercise are given in the following table. This is not a comprehensive list; you should consult your client's doctor or pharmacist if you are uncertain of the possible exercise limitations of their medications.

Medical condition	Drug type	Generic name	Brand name	Exercise precautions
Hypertension, arrhythmia, angina	ACE inhibitors	Captopril Enalapril Quinapril	Capoten Vasotec Accupril	Dehydration, dizziness, heat intolerance
	Antiadrenergic	Clonidine	Catapres	Dehydration, exercise hypotension, orthostatic hypotension, heat intolerance
Antiarrhythmic		Disopyramide	Norpace	Dizziness, heat intolerance, orthostatic hypotension
	Beta blockers	Propranolol Atenolol	Inderal Tenormin	Dizziness, heat intolerance
	Nitrates	Glyceryl trinitrate Isosorbide dinitrate	Anginine Sorbidin	Exercise hypotension, orthostatic hypotension
Anxiety, depression, insomnia	Benzodiazepines	Diazepam Temazepam Aprazolam	Valium Temaze Xanax	Dizziness, muscular incoordination
	Serotonin reuptake inhibitors	Fluoxetine Sertraline	Prozac Zoloft	Dizziness, muscular incoordination, orthostatic hypotension
Convulsions, seizures, epilepsy		Carbamazepine Phenytoin	Tegretol Dilantin	Dizziness, weakness, orthostatic hypotension, muscular incoordination
Spasticity, muscle spasms		Diazepam Dantrolene Baclofen	Valium Dantrium Baclo	Dizziness, muscular incoordination, weakness
Bladder management		Oxybutinin	Ditropan Oxytrol	Dizziness, heat intolerance

Unit 5 – Disability Act and Disability Awareness

Australian Disability Discrimination Act 1992

In Australia, people with disabilities have the same human rights as all members of the community. The Disability Discrimination Act (DDA) makes it illegal to treat a person with a disability (or their carer, relative, co-workers or friends) differently than someone without a disability. The definition of disability includes any person with a limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and restricts everyday activities. This definition includes people with physical, intellectual and sensory conditions as well as those affected by a mental disorder or a disease such as AIDS.

The Act covers areas such as employment, education, access to public buildings, provision of goods and services, accommodation, buying land, sport, membership of clubs and access to facilities. An outline of the DDA can be found at www.hreoc.gov.au/disability_rights/dda.../dda_guide.htm.

In relation to fitness centres, a person with a disability has the same right to obtain goods and use services and facilities as people without a disability. This includes sporting facilities, health services, social clubs, shops, cafes, theatres, and public transport. People with a disability also have a right to access all areas and facilities that are open to members of the public, and owners are obliged to make provisions for disabled access. This may require modification to existing buildings or designing new buildings for universal access. The only situation where disabled access does not have to be provided is when the owner or organisation can demonstrate that it will cause major difficulties or excessive costs ("unjustifiable hardship").

Complaints about discrimination against people with disabilities can be made to the Australian Human Rights Commission www.hreoc.gov.au/disability_rights/. The Commission attempts to resolve complaints by conciliation before considering legal action. The Commission also assists individuals and organisations to understand their rights and meet their legal responsibilities.

Disability Awareness

Language

Disability is not an issue that involves only a minority. Approximately 19% of Australians have some form of disability that affects their activities of daily living.

Impairment, disability and handicap are important terms used internationally.

- Impairment – A loss or abnormality of bodily function, which may be a physiological, psychological or anatomical change in a body part or organ system; an impairment is a medical condition.
- Disability - A restriction or lack of ability to perform an activity in a normal manner, which results from an impairment. The emphasis is on the practical problems faced in the performance of personal, social or occupational activities.
- Handicap – The social, behavioural and psychological consequences of disabilities. These are the disadvantages facing the individual resulting from an impairment or disability, which limits or prevents them from fulfilling a normal social role of someone of their age, sex and culture. A handicap is the limitation of opportunities to take part in the life of the community on an equal level with others.

When interacting with people with disabilities on either a social or professional level it is important to use appropriate terminology to avoid giving offense. Simple guidelines are:

- Avoid stereotypical or stigmatising depictions of people with disabilities.
- Avoid phrases and words that demean individuals with disabilities.
- Put the person first eg 'person with a disability' not 'disabled person'.

Words/ phrases to avoid	Acceptable alternatives
Words that imply a failure to reach perfection e.g. abnormal, defective, deformed.	Specify the disability.
Afflicted with (most people with disabilities don't see themselves as afflicted with).	The person has (specify the disability).
Using the impairment to define the person e.g. blind, deaf, epileptic, diseased, spastic (they are still first and foremost people).	A person who is blind/ has epilepsy.
Confined to a wheelchair, wheelchair bound (a wheelchair provides mobility not restriction).	A person who uses a wheelchair/ wheelchair user.
The disabled, the handicapped (people with a disability are not a separate subset of the population).	A person with a disability.
Cripple, crippled (negative words implying an ugly body image).	A person with a physical disability.
Physically challenged/ mentally challenged (a disability is not a challenge).	A person with a (specify the disability).
Insane, lunatic, maniac, mental patient, mentally diseased, neurotic psycho, psychotic, schizophrenic, unsound mind (derogatory terms).	A person with a psychological disability.
Mentally retarded, feeble minded, imbecile, moron (offensive and inaccurate terms).	A person with a mental disability.

Working and Communicating with people with disabilities

Interacting with people with disabilities requires common sense and simple sensitivity. A few key points are:

- Good interpersonal skills, such as active listening, are a key to success.
- Accept people with disabilities as individuals. Do not generalise about all people with disabilities from your knowledge of a few; the consequences of a disability vary considerably from person to person.
- Listen to what people say, don't assume you know what they want or what is best for them. People with disabilities are no less capable of thinking for themselves than anyone else.
- Be yourself, be natural, do not patronise or be overly helpful.
- A disability is not necessarily an illness. Do not treat people with disabilities as though they are sick. Treat them as healthy individuals.
- Focus attention on the individual's abilities, not their disabilities. The subjective feeling of living with disability can be exacerbated by the perceptions and expressions of other people.
- Speak directly to the person, not to their carer. Do not talk about the person as if they are not there. If the person with a disability has a communication problem they will usually let you know and indicate a preferred method of communicating.

- Do not assume assistance is needed, ask first. Accept the person's right to refuse help.
- Be aware of what is accessible and inaccessible to people in wheelchairs.
- Do not rush the person. They may require more time to complete a task than an able-bodied individual but this is not a negative thing.
- It is not necessary to avoid the topic of a person's disability. People with disabilities often appreciate the opportunity to explain the nature of their disability rather than have assumptions made about them. Some information will also be important to know e.g. for good exercise prescription.
- Sympathetic stares, touches or comments are rarely required, especially from strangers as it can be seen as patronising. Wheelchair use in itself, cannot be presumed a tragedy.

Wheelchair Etiquette

- Always ask the person in the wheelchair if they would like assistance before you help them i.e. use "can I help you" instead of "let me do that for you". Whilst it may appear the task is not easy, the rider has a much better awareness of their own limits than you, and unexpected assistance can often throw them off balance.
- Do not be offended if a wheelchair rider refuses your offer of assistance. It is not personal. It is often important for the rider to complete the task independently.
- When assisting a rider, always be mindful of your own safety. You are not obliged to do something you are uncomfortable with even if you initiated the offer of assistance. Instead, offer an alternative.
- When assisting a wheelchair rider, they are in charge. Ask them to explain the task first and how they would like you to help them.
- Do not move the wheelchair without the rider's permission. If they are in the way, ask them to move – you would never push an able-bodied person out of

the way. If they have transferred out of their chair, do not move it out of their reach (unless they ask) as you are removing their independence.

- Don't lean or hang on the wheelchair, this is part of the person's personal space. It can also unbalance the chair.
- Speak to the person in the chair and look at them, not the chair.
- If you are having a lengthy conversation with a person in a wheelchair, sit or kneel down to put yourself at their level.
- There is rarely a need to express sympathy to a wheelchair user. Never assume that using a wheelchair is in itself a tragedy
- There is no need to be sensitive about using words like 'walking' or 'running'. People in wheelchairs use the same words.
- Never sit in somebody else's wheelchair unless they give you permission. If they do allow you to, always remove their cushion first as it has been especially designed for them to minimise their pressure areas.
- When giving directions to somebody in a wheelchair, include information which may affect their ability to get to the destination e.g. distance, possible physical obstacles e.g. stairs, hills, poor surfaces.

SCI Barriers to exercise

There are multiple barriers to participation in exercise programs for people with SCI. Some of these barriers are physical due to limitations caused by their impairment, while others are psychosocial due to limitations imposed by the environment and other people's attitudes towards disabilities. Minimising these psychosocial barriers will be one of the easiest ways to motivate each participant in the program. An understanding and awareness of other potential physical barriers will also allow you to design the most effective exercise program for your clients. This will allow them to benefit from both the physical and psychological benefits of participating in a regular exercise program.

Physical limitations

Barriers to exercise due to physical limitations (such as impaired grip and trunk stability) can be overcome using modified equipment and techniques. It is essential that staff be trained to understand the modifications required and associated safety considerations. Physical limitations can also mean that it takes a participant longer to complete tasks. It is likely your SCI clients will not be able to complete the same number of exercises in a given timeframe as your able-bodied clients as there will be a longer time between activities required for set-up and transfers etc. Being on time for appointments may be more difficult if they're reliant on public transport.

Motivation

Although two individuals may have a similar disability it is important to understand that each individual will have different goals and motivations. The functional ability of an individual with a disability is affected by many factors: previous health and fitness, age, level of support from family and friends, financial support and personality traits. Just as you cannot assume two able-bodied individuals to be similarly motivated to exercise, you cannot assume similarity in two individuals with a disability.

Accessibility

Accessibility to buildings, facilities (e.g. toilets) and transport are obvious physical barriers to participating in physical activity program. Lack of access to information about program availability can also be a barrier. Social interaction is an important part of motivation and participation in exercise.

Social barriers

The attitudes of others to people with disabilities can be a major barrier to participation in community activities. Prejudices and stereotypes can make able-bodied people feel awkward and even fearful around people with disabilities. Conversely, wrong assumptions will affect the individual with a disability's desire to return. Educating staff about disability awareness and social interactions with these clients can overcome

this barrier so that all clients are treated with the same respect. Leading by example is a great way to educate those around you.

Lack of Experience

People with SCI may have had little experience of exercising in a gym before their accident. They may be reluctant to try a new activity, as they do not know what is expected of them, or whether staff will understand their limitations and concerns. 'Come and Try' sessions are a good way to break down these barriers as participants can see what is available for them to use, can meet staff and ask questions before committing to a program.

Financial Considerations

In Australia, over 60% of people who sustain SCI will not return to formal employment. The costs of equipment, accessible housing, transport and health care for someone with a spinal cord injury are high. Insufficient income can become a serious barrier to participation in exercise program.

UNIT 6 – WHEELCHAIR AND FACILITY ACCESS

Types of wheelchairs

There are a wide variety of wheelchairs in two basic types: manual (self-propelled) and motorised/ electric. Manual wheelchairs are fairly lightweight (between 5-20 kg) and compact, while motorised wheelchairs are larger and much heavier. Motorised wheelchairs have greater access limitations as they cannot be manoeuvred up or down steps/kerbs, and they require larger turning circles. Wheelchair type for a person with SCI depends on their level of injury, shoulder function, distance of their intended travel and whether specialised modifications are necessary, like for wheelchair athletes.

The information below is a guide to manual and motorised wheelchair access. The information is based on Australian Standards (AS) as guided by the Commonwealth Disability Discrimination Act 1992 (DDA), the Disability (Access to Premises – Buildings) Standards 2010, various State Government Disability Acts, and the Building Code of Australia (BCA). For further information check out: http://www.hreoc.gov.au/disability_rights/buildings/guidelines.htm

Parking

A larger than standard car parking bay is necessary to unload a wheelchair from a car. Take a look at the video clip of a T6 paraplegic as he manoeuvres into his car. You will note why there's a requirement for the car door to be wide open, and the consequent need for a large parking space.

<http://www.youtube.com/watch?v=b7biVXVemdU&NR=1&feature=fvwp>.

Many manual wheelchairs are carried inside or on top of the vehicle and lifted up and down using a motorised hoist. This means that the parking bay should be 2.4m wide to allow unloading space for the wheelchair, and have a height clearance of 2.5m if a rooftop hoist is used.



Example of a car rooftop hoist system. Used with permission from IKON Engineering Development Ltd (26/07/2011).

Motorised wheelchairs are most commonly loaded via a lift or ramp at the rear of a vehicle. In this case, a parking space 5m long is required. It is also important there are no kerbs or steps between the vehicle and the access route to the building.



Example of a rear wheelchair access vehicle modification. Used with kind permission from Freedom Motors Australia Pty Ltd (26/7/11).

Access routes

To accommodate all wheelchairs, main access routes need to represent a *continuous accessible path of travel* where paths/routes are 900mm wide and free of kerbs and steps. Most manual wheelchair users can negotiate kerbs and steps with assistance, but motorised wheelchairs cannot. The following video clips show: (Australian Human Rights Commission) Paraplegic negotiating a kerb, (2) Experienced T4-5 paraplegic competently climbing and descending a set of stairs; this requires a lot of training to execute so it's important to realise not everyone will be able to do these.

(1) http://www.youtube.com/results?search_query=wheelchair+up+a+kerb&aq=f

(2) <http://www.youtube.com/watch?v=eRgiz2a3Njs&playnext=1&list=PL235E75AF066D4BC2>

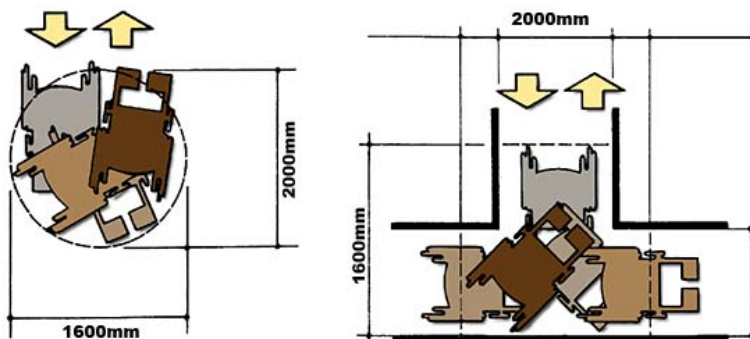
To prevent the wheelchair tipping, the slope of the access route should be less than 5% (a change in height of less than 1m over a 20m distance) with a transverse slope of no more than 2% (a change in height of less than 1m over a 50m distance).

Some manual wheelchair riders may need assistance to negotiate slopes as it will depend on their individual function; a C5 complete will struggle independently on anything other than a flat, smooth surface. Most motorised wheelchairs can climb steeper slopes however they are more prone to tipping. Remember, the majority of people with SCI have very limited trunk muscle use and therefore have problems with maintaining their own balance; disturbances that move the body away from the midline are challenging for them.

Purpose-designed ramps need to be able to carry the weight of a motorised chair and the rider, and should have a landing platform every 9 m. If the ramp edge has a vertical drop of more than 150 mm, it should have side rails installed.

Turning circle

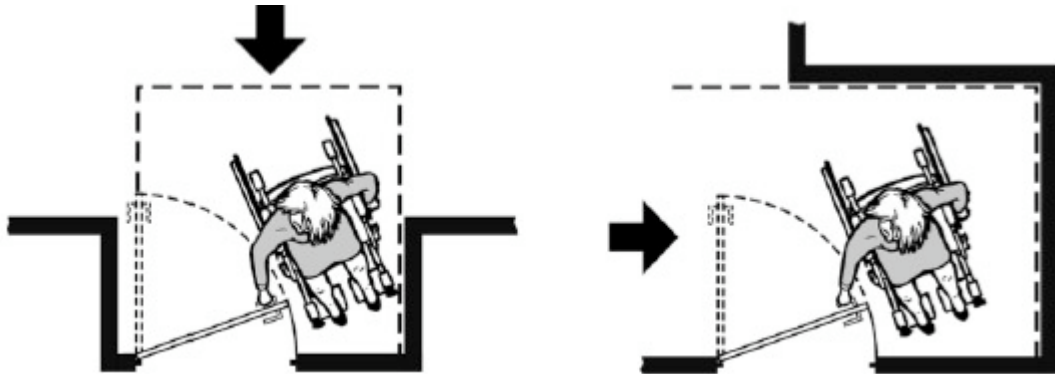
Turning a wheelchair around requires a circulation space of a minimum of 1600mm by 2000mm (AS 1428.1) or even larger with the recommended 1900mm x 2300mm (AS 1428.2).



**Wheelchair circulation access distances required according to AS 1428.1.
Modified from the American Disability Services Act images.**

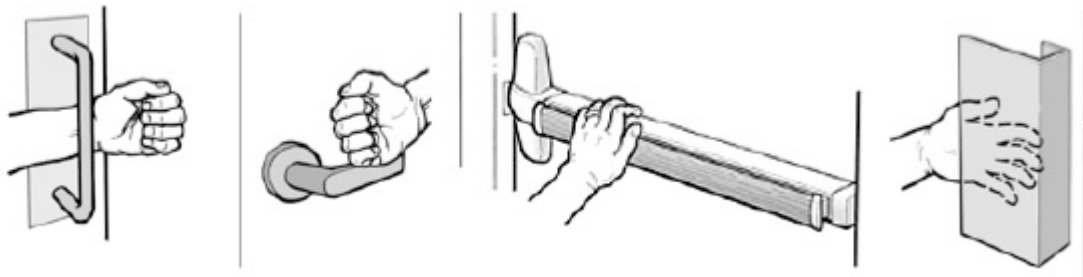
Doorways

Wheelchair accessible doorways should have a clear width of no less than an 800mm doorway opening (AS 1428.1), with an 850mm opening recommended (AS 1428.2). A revolving doorway is not considered an accessible entrance. The area in front of the doorway should be level and equivalent to a 1.6m turning/circulation area.



To manoeuvre easily through a doorway, the rider needs to be able to use both hands on their chair. If the door is too heavy, the rider will not be able to pull/ push it open enough to manoeuvre through easily. Alternatively, if a swinging door returns too quickly, it may hit the chair and/or rider as they manoeuvre through, causing injury. This is particularly important as it is not acceptable for individuals to allow the door to fall on their lower limbs or alternatively to use their foot plates to force a door open. Though they may not be able to feel a foot injury, if an injury is sustained it can be a serious problem.

Door handles should be at an accessible height and not require turning or grasping as many individuals have limited hand control; round knobs are generally not acceptable.



Toilets/ showers

The design and fit out of accessible toilets is vital for participation of people with a disability. To be accessible the toilet/shower door must be at least 900mm wide and the stall at least 1.5m long and 1.5m wide. To minimise the risk of falls the floor should be slip resistant and grab rails should be mounted on the side and rear walls. For showering, individuals with SCI will need a shower chair and most likely a movable shower head.

It is preferable for hand basins to have knee space underneath, with water pipes and abrasive surfaces below the sink insulated to prevent burns and cuts.

The ability to go to the toilet is an important part of independence for an individual with SCI. Though some individuals use indwelling catheters, it is important they have access to a toilet in case of an emergency or if it needs to be flushed. If your facility doesn't have a wheelchair accessible toilet, determine the next best option e.g. is there one in a building nearby or can alterations be made to the current facilities to make them more wheelchair accessible?

UNIT 7 - SAFETY, RISK MANAGEMENT, INJURY PREVENTION AND EMERGENCY PROCEDURES

What is this unit about: Safety - be prepared

What you have to do: Have the Risk Management Checklist and Emergency Procedures Booklet or download them from the T3-SCI website on Unit 7. Complete the safety booklet for your gym situation. We want you to make the gym as safe as possible. We want you to be prepared for common problems associated with exercises and individuals with SCI.

What we will do: We will hand out a hard copy of the Emergency Procedures booklet for you and your gym. You are now at the point where we start to identify an individual living in the local community so as to organise a meeting. If we cannot find someone then we may have difficulty progressing into the practical part of the program; if you have any knowledge of a person with SCI who might be a potential recruit for the program, then let your node leader know ASAP.

You can find all the relevant information of this Unit in the Emergency Procedures Booklet.

Unit 8 - Exercise training following SCI

What is this unit about: Exercise and planning

What you have to do: Read the informative pages and any associated links you choose. You will need to download the exercise image documents found in Unit 8 and retain them as electronic files that you can use to develop your program assignment. You should also download the exemplar example of a program designed for a C7 complete person to improve their wheelchair-to-other transfers. When considering your own programming, be conscious that SCI cases cannot be treated as a group because such diversity exists in their capacities. As such, this unit is not necessarily the gold standard but more of an ideas base for those of you who are not experienced in SCI rehabilitation.

What we will do: While you are working on this unit the Node leader is working hard to match you with someone in your gym. Unless you already have someone to train! Make sure you go to some of the web links and check out some rehabilitation program on the internet, in addition to the ones developed on T3 SCI.

Before we start...

The main focus of T3 is to break down barriers for individuals with SCI to participate in physical activity. Many people feel uncomfortable walking into a gymnasium for the first time, being in a wheelchair may be even more difficult.

This training program is aimed at educating fitness trainers to:

- Be comfortable when engaging with individuals in wheelchairs,
- Understand some of the issues facing people with SCI, and
- Assist individuals with SCI to achieve their physical activity and healthy lifestyle goals.

The next section examines the physical effects and benefits of exercise for individuals with SCI.

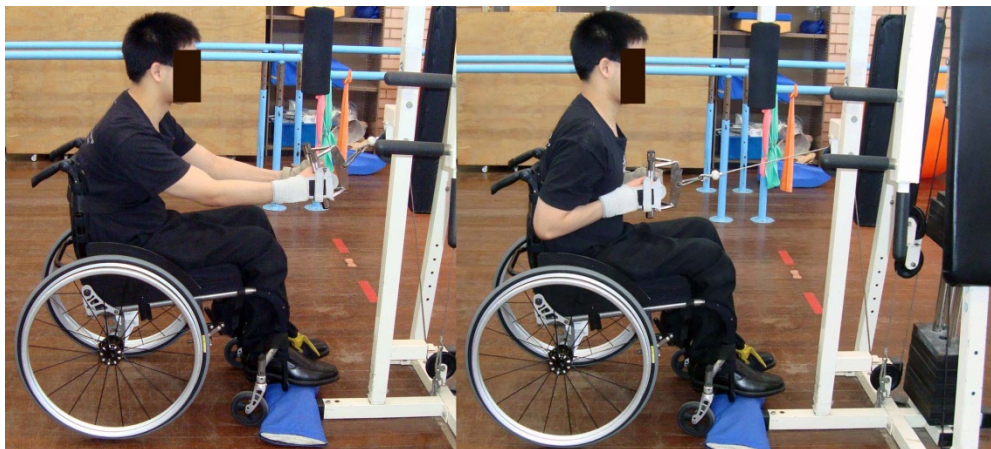
Ultimately, **participating in any form of physical activity in a public setting with a great trainer will have positive outcomes.**

Check out the types of exercises you could consider using on our website:
<http://curtintrainthetrainer.cloudapp.net/Unit/Index/7/1>

1. [Stretching](#),
2. [Cardiovascular](#),
3. [Balance or transferring](#), and
4. [Upper limbs and trunk](#).

Remember that the T3 SCI images are copyright and should not be distributed outside the T3 SCI program.

[Also check out a good program that has been designed by a T3 SCI trainer](#); you should be working toward something along these lines in your own program development ideas.



Seated row by a C6 complete tetraplegic

The need for exercise training following SCI

Most individuals with SCI live an increasingly sedentary lifestyle when compared to their able-bodied counterparts. This is due to both internal and external barriers.

When the metabolic changes after SCI are coupled with decreased physical activity, predisposition and risk for metabolic dysfunction, cardiovascular disease and respiratory problems are increased. As known contributors to SCI mortality, efforts to limit these disease states should be made; improving physical activity levels appears to be a key method.

Studies have shown that 25% of young adults with SCI who are classified as “healthy”, fail to satisfy a level of physical fitness required to comfortably carry out their activities of daily living (ADL). Cardiovascular training following SCI can improve endurance, respiration, glucose tolerance and lipid profile. Resistance training following SCI has been shown to improve power, strength, physical function, and wheelchair skills, while decreasing levels of pain, stress, and depression. These changes have the potential to improve health and quality of life.

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Understanding biomechanics of common activities of daily living

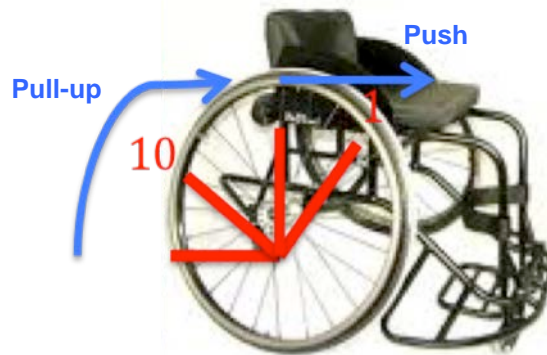
Wheelchair propulsion

Depending on the level of the lesion, individuals may have full or partial upper arm muscle function. Individuals who have strong biceps and triceps can use both elbow flexion and extension to control the wheelchair.

Reaching back and pulling up the wheel from the 9-10 o'clock position initiates **pull/push propulsion**. Individuals without hand or finger function are not able to grip the wheel and instead use pressure and traction from the heel of their hand against the wheel rim. Many wheelchair users wear gloves to protect their skin.

As both hands reach the 12 o'clock position, individuals with triceps function (not C5 or C6) will follow with a powerful push through to the 1-2 o'clock position.

The push phase requires muscle activity from: anterior deltoid, pectorals, shoulder rotators, serratus anterior, biceps brachii and triceps brachii.



Due to the high strength demand to push a wheelchair against ground friction, these muscles are typically strong and may be tight. As a consequence, there is an increased risk of shoulder impingement secondary to forward repositioning of the humeral head and associated scapula protraction.

The **recovery phase** returns the arms to their starting position. The active muscles of the recovery phase are: middle and posterior deltoid, shoulder rotators, middle trapezius and triceps brachii. Less muscular effort is required in the recovery phase as the muscles are working against minimal resistance. Consequently, these

muscles are often weaker than the push phase muscles, which may lead to muscle imbalance and possible shoulder injury.

The following link shows the hand placement to start the pull-up phase and into the push phase.
http://www.youtube.com/watch?v=K7HLUYtE2ql&playnext=1&videos=RcqPpcUfDnE&feature=mfu_in_order.

As load is increased e.g. wheeling up hills or over soft surfaces, the demand on the anterior shoulder and triceps is increased.
http://www.youtube.com/watch?v=JjZ_3a61HU8.

Take a look at this woman with a C7 complete SCI as she negotiates different terrains in her wheelchair; there is a marked difference in energy output from the gravel path to the grass.

<http://www.youtube.com/watch?v=AxLQgoSxNJw>.

Weight lift/transfer

Lifting body weight is an essential task for pressure relief or transfer between surfaces. Method and ability to achieve independent weight transfer is dependent on level and completeness of the individual's SCI. Take a look at this young C6 tetraplegic guy as he shows several mobility transfers.
http://www.youtube.com/watch?v=7_EGCPmngB8

Essential daily skills are physically demanding, even sitting up in bed. This needs to be considered in program planning and may form part of your discussions about goals.

Generally, weight shift from a seated position requires functioning rotator cuff, triceps brachii, pectorals and latissimus dorsi. However, it is possible through efficient use of levers and body loading, to independently weight transfer without full function of these muscles. That said, it is important not to overestimate a person's abilities; they will know what they can and can't do physically.

The link to follow presents a video of a C6-C7 incomplete man independently transferring between his wheelchair and bed. He has limited triceps function in his left arm, and none in his right. He does not have hand function bilaterally and uses his

elbows as levers to lift his legs with his forearms. Notice how he needs to lock his elbows straight, balance his body weight through the length of his bones, and use his minimal latissimus dorsi and momentum to lift his body weight.

<http://www.youtube.com/watch?v=h9EfpZe6l8k>.

Here's an example of a paraplegic transferring into a car. Readjusting his position in his seat appears almost effortless in comparison to the two previous guys.

http://www.youtube.com/watch?v=5fw_VqwxrRU&feature=related.

Reaching

Reaching outside of the base of support (to one side or across the body) requires good trunk strength to control balance. Many individuals with SCI have impaired trunk function, which affects their ability to reach for objects. When reaching, people with SCI will hold on to their chair with one arm as a counterbalance to reaching with the other. This prevents them falling out of the chair and allows a pull back action to return to sitting upright. Individuals with a high-level injury may also use head movements to initiate trunk momentum, as you would have noticed in the first video clip above.

Tenodesis protection. Tenodesis refers to the passive finger flexion that occurs in the hand when the wrist is fully extended. Give it a try yourself: relax your hand into wrist flexion with your fingers relatively straight, extend your wrist; notice how your fingers flex at each joint. Tenodesis is a critical functional necessity in high-level tetraplegics, particularly for C6-C8s; it must be protected by considered hand placements.

Early rehabilitation after SCI for tetraplegics focuses on allowing shortening of the finger flexor tendons and ligaments such that they encourage finger bending when the wrist is moved into extension. Tenodesis is functionally very important to individuals with high-level SCI who use this action for grasping objects. If the wrist and finger flexors are stretched, the tenodesis becomes ineffective and can significantly reduce function. Thus, it is important to make sure that the SCI individual never passively stretches the wrist and finger flexors together or rests in full hand and wrist extension. It

is unlikely that short term stretching will make a change but the habit of resting in passive finger flexion with wrist extension should be encouraged.

This is the video of the C5-6 transferring onto the bed <http://www.youtube.com/watch?v=h9EfpZe6l8k>. Watch it again and notice how he only puts weight through his hand when it's in a fist. This is to protect his tenodesis. Also note his apparent gripping as he places his right hand on the wheelchair; it looks like he has hand function but this is only as a consequence of a rehabilitated tenodesis.

Assistive devices. Most of your SCI clients will have some degree of impaired trunk control and will use their upper limbs to assist with balance. During upper limb exercise, they may require an additional trunk strap to maintain balance or may hold on to their chair with one arm whilst exercising the other. Some individuals will also have some degree of impaired hand function. Assistive devices such as straps or weight cuffs may be used to help your client grasp the equipment.



Images demonstrating types of hand and trunk straps to facilitate equipment use.

Finally, some individuals may use assistive devices when exercising. Compression stockings and abdominal binders will improve venous return and decrease blood pooling in the lower limbs. This can decrease the risk of orthostatic hypotension (lightheadedness or fainting when moving from reclined to upright or sitting

positions). Abdominal binders can also assist with respiration by mimicking tonic abdominal muscles.

An extreme example, but checkout the straps needed to keep a wheelchair rugby player in their chair during the game.



Given the biomechanics of these primary functional tasks, the important muscle groups for resistance training are:

- Shoulder rotators (external > internal);
- Shoulder adductors;
- Scapula retractors;
- Shoulder girdle depressors;
- Shoulder extenders and flexors;
- Elbow extensors and flexors;
- and Trunk stabilizers.

Ultimately, this means that a general upper limb exercise program modified for the balance limitations and level of innervation for each person would best suit this client group.

Consideration of the muscles supporting and moving both sides of the joint should be paramount.

Physiological effects of exercise

Below is a comparative summary of the physiological effects of exercise in the able-bodied and SCI populations.

Summary of the physiological effects of exercise.

Effect on	Able-bodied population	SCI
Heart rate	Increases. Approx HRmax = 220 - age	<ul style="list-style-type: none"> • T6 and above: Decreased acceleration and deceleration. Approx HRmax is less than 130bpm. • Below T6: Normal to exaggerated HR response. Approx HRmax = 200-age
Respiration	Increases to maximize blood oxygen levels.	<ul style="list-style-type: none"> • Increases may be limited by denervation of the respiratory muscles. • Blood oxygen supplies to the working muscles are limited and cause regional limitation to muscle endurance and strength. • Arm activities further limit respiratory capacity as the accessory muscles of respiration are used to produce arm movement and cannot contribute to ribcage expansion.
Blood pressure	Systolic BP slightly increases; Diastolic BP remains the same.	<ul style="list-style-type: none"> • May decrease as blood pools in the lower limbs due to reduced venous return.
Thermoregulation	Active sweating and dilation of superficial blood vessels to maintain a stable body temperature.	<ul style="list-style-type: none"> • There is no active autonomic thermoregulation via sweating below the injury.
Bladder and bowel	Increased urine output and bowel activity.	<ul style="list-style-type: none"> • Increased urine output and bowel activity.

The impact of physiological effects on physical activity training

The physiological effects of exercise have important consequences for exercise training in the SCI population. The extent of improvements in cardiovascular fitness and muscular strength are likely to be less for an individual with SCI than their able-bodied

counterparts. This is important, as the expectations of both the client and trainer must always remain realistic.

The influence of autonomic dysfunction is most important in regards to heart rate and thermoregulation when exercising. Maximum heart rate, heart rate range and acceleration/deceleration are limited by the autonomic disturbance and are therefore not reliable measures of fitness or exercise intensity. As individuals with SCI have limited ability to thermoregulate, they must exercise in a temperate environment and be monitored for signs of heat stress.

Individuals with SCI also have decreased physiological reserves, dependent on the available muscle mass of the person. They can have large day-to-day variations in fitness and performance, which is most apparent in high level SCI. Again this is important in the maintenance of realistic expectations as the individual may not always be able to better their previous performance. People with SCI should not exercise when they are sick as they can fatigue quickly thereby increasing risk of injury. Physical activity can also exacerbate the illness and delay recovery.

Arm vs. leg exercise

Muscle groups in the lower limbs are larger than those in the upper limbs. Therefore the maximal strength and power output of an individual's upper limbs is less than that of their lower limbs. Decreased mechanical efficiency of the upper limbs means these muscles still require the same oxygen supplies as the lower limbs, yet produce a smaller force. At the same maximal oxygen uptake (VO₂ max) upper limb power output is only 80% of lower limb power output. As such, there is a much greater physiological cost when exercising with the upper limbs compared to the lower limbs. Arm exercise also tends to be limited by regional muscle fatigue rather than cardiovascular fitness due to differences in muscle mass and mechanical efficiency.

A second limitation of arm exercise when compared to leg exercise pertains to respiratory capacity. During leg exercise, the accessory muscles of respiration are used to increase respiration by moving the ribcage. During arm exercise, some of these muscles are required to produce the upper limb movement thus they cannot be used to effectively move the ribcage and increase ventilation. This is further exacerbated in

high-level SCI as the paralysed or weak torso cannot provide a stable base for movement, thus the upper body must also be used to balance and control the position of the trunk. This causes further limitation to the upper limbs ability to contribute to respiration.

Continuous arm exercise, such as ergometer training, has the potential to improve some aspects of cardiovascular fitness, e.g. respiratory capacity and regional muscle function. These gains will be reflected in overall health and functional improvement. Importantly however, increased capacity for continuous arm exercise cannot be used as an isolated measure of cardiovascular fitness due the involvement of the other potentially limiting factors.

Physiological adaptations following exercise training in an individual with SCI

Aerobic capacity/ Aerobic fitness

Aerobic fitness improvements are related to the SCI body's ability to maximize efficiency in oxygen uptake and use by the muscles. Following exercise training, individuals with SCI have an increased VO₂ max due to both; increased strength of the respiratory muscles to expand the lungs, and decreased resistance of the lungs and ribcage to expansion. VO₂ max is inversely proportional to level of injury, meaning, the further down the spine the injury is, the greater the lung capacity. The oxygen demands of working muscles decrease as they become more efficient, thereby minimizing muscle fatigue as a limitation to exercise capacity. Cardiorespiratory endurance with upper limb activities also improves, directly increasing the individuals physical work capacity.

For high-level SCI (above T6) there is minimal adaptation to the cardiovascular system. In this population, cardiovascular response (heart rate acceleration/deceleration and vascular patency) is a reflection of the autonomic dysfunction resulting from the injury and not the individual's level of fitness. For SCI below T6, cardiovascular adaptations will be similar to those of an able-bodied exerciser although there will be limited effect on vascular activity below the level of injury.

Respiration

Respiratory improvements are seen in increased total lung capacity and respiratory reserve. These are likely the result of improved posture and breathing pattern, improving the ease with which the lungs expand. Improvement in respiratory muscle strength also decreases the physiological cost of breathing, which can be reflected in a noticeable decrease in breathlessness for the individual and an increased work capacity.

Metabolic System

As in the able-bodied population, increasing activity levels will decrease fat mass. Due to the metabolic disturbance following SCI however, this will not be to the same extent, thus health outcomes such as BMI and skin folds are not relevant, and expectations must be moderated. The most important physiological adaptations to the metabolic system are improved lipid profile and insulin sensitivity. This decreases the individual's risk of diabetes, cardiovascular disease and coronary heart disease.

Muscle

As in the able-bodied population, exercise training increases muscle strength, power and endurance. This is reflected in improved posture and respiratory function, decreasing the individual's risk of musculoskeletal injury. It is important to understand that only innervated muscles can be strengthened. Therefore, the higher the SCI, the fewer muscles are available for strengthening.

Many functional tasks undertaken by individuals with SCI require motor skills such as good balance and coordination. General strengthening exercises are focused on muscle capacity training; however there will also be a cross-training effect on trunk balance and motor control. For example, a simple biceps curl will also place a balance demand on the trunk if the individual has moderate sitting balance. Improved muscle function and motor skills will directly improve functional abilities and physical work capacity, and decrease fatigue.

Function

One of the most important outcomes of exercise training is its effect on functional abilities. Physiological adaptations of the cardiovascular, respiratory and musculoskeletal systems will all contribute to general improvement of the individual's efficiency and independence with activities of daily living. For specific functional improvement however, good specific skills are often required.

Psychological state

There is significant evidence that exercise training can improve the psychological state of all individuals. Exercise, along with resulting functional improvements, can decrease negative mood states and depressive symptoms and increase quality of life. Interacting with an engaging trainer in a community setting is believed to be a powerful factor in psychological wellness.

Effects of SCI secondary conditions on exercise response

Urinary tract infections (UTI)

Urinary tract infections are common in individuals with SCI, particularly if they use an indwelling catheter. Symptoms include increased urine output, increased temperature, increased muscular spasms in lower extremities, headache, nausea and fatigue. Individuals with a UTI should not exercise while febrile as this will delay recovery and increase their risk of heat stress, dehydration and more critically, autonomic dysreflexia.

Fatigue

Many individuals with SCI suffer from fatigue due to poor sleeping patterns and the necessity of waking in the night to catheterize and/or perform pressure relief. Fatigue will affect exercise performance, however low intensity exercise has also been shown to limit the effects of fatigue.

Pain

Neuropathic pain is a common consequence of spinal cord injury and is principally treated by medication and activity modification. Pain levels can vary from day to day depending on fatigue, emotional state, and other complications such as bladder, bowel and skin problems. Varying pain levels may affect day-to-day exercise capacity, but pain should never preclude exercise ability. Low intensity exercise can decrease pain levels but each individual should also have a pain management program designed by their doctor.

Summary

We all know exercise is good for physical and mental well-being. This is true for everybody. Depending on the level and completeness of their injury, individuals with SCI will have differing capacities for aerobic exercise and differing available muscles for resistance training. In general however, most individuals with SCI who are not already involved in sport or structured exercise program tend to be extremely inactive. Therefore, even short periods of exercise on a regular basis will add to their levels of activity. Importantly, some individuals are likely to use more energy getting to and from the gym, than they will doing exercises in the gym. This is important as participating in physical activity to improve general quality of life and health does not have to be a big effort and commitment.

UNIT 9 - DESIGNING AN EXERCISE PROGRAM

What is this unit about? - *The exercise program*

What you need to do: Think about the basic principles of fitness training and rehabilitation design and understand how this may be different with people with a SCI. You will need to complete your exercise program assignment after you have met your client. This occurs later in the process but this Unit exposes you to several exercises and concepts relevant to developing your own program. Useful exercises are added to an ever-growing database that you can select from for your own program to be submitted after completion of Unit 10.

What we will do: The node leader will provide assistance and feedback throughout the program. Should you have any questions then ask.

Introduction

In general, the same principles of fitness training are to be followed for individuals with SCI as for the able-bodied population. The main objective is to engage in a set of appropriately planned activities that meet the goals of the individual to improve their well-being and general health.

The following section focuses on improving physical activity and general health through a standard exercise program that intends to fulfil the majority of goals set by your clients. Requests for specific goal attainment should be respected and programs tailored to meet individual needs.

The overarching aims of the exercise program you will design are to improve the fitness, strength and functional abilities of your client. This will typically require two components, endurance training to improve cardiovascular fitness, and resistance training to improve muscle performance. In the SCI population, success has been seen with circuit training that addresses both of these components. Initially, training at low to moderate intensity can have significant positive results as these individuals are typically unfit and de-conditioned.



C6-7 performing seated pushdowns to train for wheelchair transfers

Client Assessment

Before commencing training, it's important to know what your client wants to get out of the program. Is it to get fit, to improve functional abilities, or to maintain what they already have? The goals you and your client develop will be used to direct the program. They will also act to measure the outcomes of the training. Even if your client has a very narrow focus for their training, it is important to also provide all the general elements of an exercise program to ensure variation in training and a wide scope of task. This will challenge the client and keep them interested in exercising over time. As the trainer, you may be focused on the strength and endurance improvements of your client. The improvements your client will notice will be the functional differences these strength and fitness gains reflect. Goal setting is addressed in Unit 10.

Before beginning the exercise program, it is important you are well acquainted with your client and their condition. Your knowledge of SCI and the functional expectations of the different levels of injury will enable you to design a safe and relevant regimen. The client's information will be gathered on their first visit or during a phone interview prior to training. The pre-exercise client assessment form (insert here) is a good guide to the information you need to get from your client. Every person is different and you both may find it difficult to discuss some of the required issues. However, it is important to have the information. The interview should be treated with an understanding that you are the individual learning about SCI and that together you and the client will achieve their goals.

It is also important to be aware of any variation in your client's wellbeing each session before they exercise. Ask how they are feeling generally? Remember illness has a much more devastating affect after SCI and that these individuals should not

be exercising if they are sick. Ask how they felt after the last session? This is important to know how hard they can be challenged during the training session.

Potential questions to ask your client prior to commencing their physical activity program.

Area	Relevant information
Medical history	<ul style="list-style-type: none"> - injury factors: type, level, surgical intervention e.g. rods - incidence of autonomic dysreflexia and the individual's specific management plan - medications
Physical activity history	<ul style="list-style-type: none"> - regular levels of physical activity - approximate levels of endurance e.g. how far can they wheel before fatigue - previous injuries with exercise programs
Spasticity	<ul style="list-style-type: none"> - which muscles are affected? - what triggers spasticity? - does it change with exercise?
Balance and trunk stability	<ul style="list-style-type: none"> - can they sit unsupported? - do they require a trunk strap to stay upright when exercising their upper limbs?
Functional level	<ul style="list-style-type: none"> - how do they transfer? - how much assistance do they require? - what are the functional expectations for their level and type of injury?
Muscle function	<ul style="list-style-type: none"> - which muscles are innervated - which muscles need to be trained to improve ADL functions - do they have existing muscle imbalance? - do they have existing muscle weakness?
Range of motion	<ul style="list-style-type: none"> - do they have any range restrictions? - do they have internal fixation rods which limit trunk movements i.e. flexion, extension, rotation, side flexion
Hand function	<ul style="list-style-type: none"> - do they need assistive devices to grasp equipment/weights? - Has a functional tenodesis been established?
Pain	<ul style="list-style-type: none"> - do they have pain? where? - are there any movements or exercises that increase pain?
Autonomic Dysreflexia	<ul style="list-style-type: none"> - have they ever had AD? - were they aware of it happening? - has it ever been triggered by exercise? - what is their management plan?
Sensation	<ul style="list-style-type: none"> - where do they lack sensation? - what areas do they need to actively protect from injury?
Referral?	<ul style="list-style-type: none"> - have you been advised to exercise? - have you ever had a problem exercising? - are there exercises that you have been told not to do? Why?

Additional Considerations

Injury level and completeness

Understanding the lesion level and injury type of your client is key to designing their exercise program. Their muscle innervation and abilities will be the starting point from where you will then make goals and determine exercises relevant to their individual circumstance.

Most of the information in this learning module is directed at training individuals with upper limb and/or trunk dysfunction. If your client has a low-level or incomplete injury, they may have enough muscle activity to control some lower limb movements, or to even stand or walk short distances. These individuals will still be heavily dependent on their upper limbs and should be prescribed upper limb activities. Their exercise program might also incorporate cardiovascular and/or resistance exercises that use and challenge any innervated lower limb muscles.

Muscle imbalance

Muscle imbalance occurs when there is an uneven pull of the opposing muscles on either side of a joint. It can lead to inappropriate or inefficient postural change and pain. There are two possible causes, the first being innervation imbalance, which may leave some muscle groups weak (paresis), and the second being poor training programs biasing one muscle group over another. All trainers working in gymnasiums know that some muscles are easier to train than others, and that all clients have their favourite exercises. For example knee extensors (quads) are often preferred over knee flexors (hamstrings). This has the potential to develop muscle strength imbalances. Due to the nature of SCI, **innervation imbalance is common and irreversible.**

Your role is to ensure there is a balance of muscle focus in the training programme so it does not create or further exacerbate imbalance problems. In this population, the most common imbalances are around the shoulders and trunk.

Movement limitation

Surgical fixation is common following spinal injury. All individuals with SCI should be aware of the importance of maintaining passive range of motion in their

affected limbs, and many will have been given a program by their physiotherapist to prevent developing range limitations. Whilst passive stretching may be incorporated in your program, if limitation to joint range is identified as a significant problem, the client should seek professional assistance from a physiotherapist for a separate home mobilisation program. Remember the importance of tenodesis for hand function.

Stretching joints that have limited sensation needs to be undertaken with caution and low load stretching should be used to avoid soft tissue risk. Remember, a person with SCI may not be able to feel their skin stretching beyond its limits, making skin tearing a possibility. There is limited scientific evidence supporting the ability to change muscle length with relatively short term stretching. If incorporated into the exercise program there may be a maintenance effect of stopping contracture progression.

Back extensors and hamstring length

The long back extensors and hamstrings are a particularly important muscle group in this population. They are important for posture maintenance and are required for balance. For example, relatively shortened back extensors will encourage a more erect trunk in seated postures. Stretching these muscle groups should be minimised as it can decrease support for upright sitting. If excessive tightness is limiting functions such as dressing, reaching to the ground or transferring, the client should be referred to a physiotherapist for a suitable stretching program.



Long sitting enabled by appropriately shortened back extensors and hamstrings.

Components of circuit training

Resistance Training Exercises

Resistance training induces physiological change based on the **SAID principle** – **S**pecific **A**daptation to **I**mposed **D**emand. The idea is to create progressive overload for the muscle group at work by manipulating the *frequency*, *duration* or *load* of the activity. This aims for muscle adaption in the form of increased number and size of muscle fibres. A resistance training program can bias strength, endurance or power depending on the specificity of the activity.

Muscle atrophy or hypertrophy is a continuous process. When a muscle adapts in response to a training program it will only maintain improvement if regularly used. If the individual stops training and the demand on the muscle group decreases, it will atrophy back to its pre-training capacity. In essence, the individual must “use it or lose it”. Practically this means that at some stage the focus of your program may change from improvement to maintenance.

There are numerous “optimal” configurations and combinations of sets and repetitions for resistance training. All programs are focussed on improving muscle performance – either strength (and muscle size – hypertrophy) or endurance. In general, the heavier the resistance, the greater the muscle hypertrophy and strength (high load and low repetitions). Routines with high repetitions and low loads in each set are generally considered to target muscle endurance. Trainers are free to use any model of resistance training they wish. One model is described below.

The 8-15 programme

The 8-15 program is a hybrid model that covers both strength and endurance principles. It aims to minimise the need to re-set the primary load on the machines by using repetitions to provide the overload. Large changes in load occur when the client reaches a specific endurance capacity. The protocol for each resistance exercise is 3 sets of 8-15RM (Repetitions Max) load.

RM loading is specific to the capacity of the individual. 1RM is the load one can complete one repetition at maximal effort. 5RM is the load one can complete five repetitions at maximal effort. As the individual progresses through the programme and their muscle capacity increases, their RM loads will increase.

Initially, the load for each exercise is set at 8RM i.e. the client can complete 8 repetitions with good form before they completely fatigue. They should be able to complete the full 8 repetitions for the first set, but may do less on subsequent sets due to fatigue. This same load is used for each subsequent session, and the client aims to do as many repetitions as possible in each set until fatigue. As they improve, the number of repetitions they can perform should increase. When the client can complete 3 sets of 15 repetitions with this load, the load is increased for their next session to the new 8RM, and the process is repeated. Initially this protocol targets strength improvements, and then moves into an endurance phase. This protocol removes the need to constantly change weights and gives immediate feedback on improvements.

Fatigue

If post exercise fatigue regularly interferes with the individual's daily life, modifications to the load and repetitions may be required. The load and repetitions may be reduced but the program should continue based on 8-15 principles. If the client is occasionally tired at the start of a session due to poor sleep or other health issues, the resistance dose for the day may be reduced. If the individual has a focus on strength, it is better to keep the high load but to reduce the number of repetitions and sets. If the individual has a focus on endurance, keep the number of repetitions and reduce the load, always training with good form.

If exercise form is questionable and unable to be altered in a session, it may be better to skip resistance training and to undertake other skills-based activities instead. You should expect that health fluctuations will affect day-to-day performance; outperforming previous effort is not always possible.

Exercise position

Exercising in reclined positions provides extra trunk support and can enhance venous return. It will improve respiration and decrease HR for a given submaximal load. It can also reduce shoulder pain by improving scapula stabilization. Conversely, it will increase time between exercises due to the required transfers,

and may increase the risk of orthostatic hypotension due to the repeated position changes. Thus, it may not be optimal for circuit training with all individuals.

Initially resistance exercises should be prescribed in upright sitting. If your client is having difficulty with balance, orthostatic hypotension during the exercises, or are reporting shoulder pain, exercises in a reclined position could be considered an alternative.

Suitable exercises for resistance training

The selection of exercises used for resistance training should be based on the individual's goals and their identified limiting factors e.g. strength of a particular muscle group. Due to the functional demands and typical presentation of individuals with SCI who use a wheelchair, the following muscle groups should be considered for training:

- Shoulder rotators (external > internal)
- Shoulder adductors
- Scapula retractors
- Shoulder girdle depressors
- Shoulder extensors > shoulder flexors
- Elbow extensors
- Elbow flexors
- Trunk stabilizers

Exercises should begin with the arms as close to the normal anatomical (glenohumeral) plane as possible. This is where the upper arm (humerus) is positioned slightly forward of the trunk (about 20-30°) rather than directly by the side. Strengthening exercises with the arms above 90° may increase the risk of impingement symptoms, particularly in repetitive actions.

Ideas for exercises for wheelchair users can be found at <http://www.physiotherapyexercises.com/>. Simply select the level of injury of your client and the muscle groups you wish to focus on.

Also try this USA site for wheelchair bodybuilders (http://www.nickfitness.com/exercise_database) that lists and illustrates gym-based exercises to target specific muscle groups.

Be aware, there are a vast number of exercises available, however not all of them are suitable for this program. Use your discretion when selecting exercises and consult your node leader if you are unsure.

Equipment selection

Equipment utility according to availability of machines, resistance bands, pulleys and free weights.

	Machines	Resistance bands	Pulleys	Free weights
Movement limited to one direction	Yes. No active stabilization required.	No. Active stabilization required.	No. Active stabilization required.	No. Active stabilization required.
Allows unilateral movement	Usually not.	Yes.	Yes.	Yes.
Wheelchair accessible	If there is sufficient clearance to manoeuvre around and transfer onto.	Yes.	Yes.	Yes.
Completed sitting in the chair.	Only if seat is removable.	Yes.	Yes.	Yes.
Safe	If the seat is wide enough and there is sufficient support.	Yes. Additional support may be required.	Yes. Additional support may be required.	Yes. Additional support may be required.
Controlled load	Yes. But some weight increments may not be suitable for weak clients	No. Load dependent on band and distance from attachment.	Yes.	Yes.
Independent set-up	Depends on machine and if the client can reach without standing.	Depends on client's hand function, environment.	Depends on exercise, and the required line of pull.	Depends on gym environment.
Portable	No.	Yes.	Usually not.	Yes.
Cost	Expensive.	Inexpensive.	Range.	Range.
Trunk activity	No. Usually have full trunk support.	Yes. Can be manipulated with the use of straps.	Yes. Can be manipulated with the use of straps	Yes. Can be manipulated with the use of straps
Home use	Usually not.	Yes.	Usually not.	Yes.

Cardiovascular (aerobic) training

Aerobic training aims to improve function and efficiency of the respiratory and cardiovascular systems to increase work/ exercise capacity. The best activities for aerobic adaptation are cyclical activities of large muscle mass e.g. legs and trunk. These are then used in either LSD training (long slow distance) or interval training.

In SCI (especially high-level), the loss of large muscle mass is a critical limitation for improving aerobic capacity. Local fatigue of the available peripheral small muscle groups occurs before central cardiovascular/respiratory fatigue. This means the aerobic barrier is rarely challenged. As a result, interval training and circuit training are generally better for this population as the peripheral limitation is minimised by alternating the working muscles while there is still demand on the aerobic systems.

Heart rate is not a reliable measure of exercise intensity for SCI to T6 and above as a consequence of autonomic disturbance. Therefore, cardiovascular training intensity is based on the modified Rate of Perceived Exertion (RPE, or Borg Scale). There is good correlation between RPE and VO_2 in paraplegic populations.

Rate of Perceived Exertion

The 15-point RPE is a simple measure of exercise intensity available to this program. It allows the client to maintain an awareness of effort and potentially recognise generalised malaise or fatigue. As the client improves in fitness, they will be working at a higher level of exercise for the same RPE. This provides the overload required to improve fitness and allows the RPE levels to remain relevant for the entirety of the program. For ease of use, the client should have a good understanding of the RPE scale and the physiological indicators of the levels of exercise (as seen below in Table 9.3).

Rating of Perceived Exertion (Borg) 15-point Scale.

Intensity	RPE	Physiological Indicators
	6 no exertion	
	7 extremely light	
Light	8	Able to sing
	9 very light	
	10	
	11 light	
Moderate	12	Can easily maintain a conversation but unable to sing
	13 somewhat hard	
Hard	14	Slightly breathless but able to maintain conversation
	15 hard (heavy)	
Very hard	16	Unable to talk
	17 very hard	
	18	
	19 extremely hard	
	20 maximal exertion	

For SCI below T6, the heart rate response to exercise approximates normal. Though the RPE scale is still relevant and easy to use for this population, percentage of HR max is an alternative way to measure exercise intensity. The following table shows the ACSM recommendations for exercise HR in this population.

ACSM exercise heart rate recommendations in the below T6 SCI population.

Age (yrs)	Moderate activity HR (bpm) RPE = 12 - 13	Vigorous activity HR (bpm) RPE = 14 - 16
20	110-140	140-160
25	107-137	137-156
30	105-133	133-152
35	102-130	130-148
40	99-126	126-144
45	96-123	123-140
50	94-119	119-136
55	91-116	116-132
60	88-112	112-128
65	85-109	109-124
70	83-105	105-120
75	80-102	102-116
80	77-98	98-112

Depending on the fitness level and motivation of the client, the exercise sessions can be structured in one of two ways, which parallel our two types of aerobic training.

LSD training uses low to moderate energy requirements to generate aerobic activity for a long period e.g. 30 to 60 minutes. It is a good way to build a foundation of muscle strength and endurance though better outcomes are usually seen with greater effort (intensity). To structure a training session based on LSD training the cardiovascular and resistance training exercises are separated. Longer steady state periods of cardiovascular activity are used (approximately 10-30 minutes duration depending on the client) at a moderate level of intensity (12-13 on the RPE). This structure is good for particularly deconditioned clients or high-level injuries as effort is low and rest periods can be increased to reduce fatigue.

Interval training is a more effective system of aerobic exercise although it requires more motivated clients. A training session based on interval training alternates cardiovascular and resistance training stations. Cardiovascular stations are shorter, of 3-5 minutes duration, and the client is working at a moderate to high level of intensity (13-15 on the RPE scale). If the client is motivated, they may

incorporate a short period of higher intensity exercise (16-17 on the RPE) to maximise training effects. The general design includes utilising the largest muscle mass possible, alternating limbs and muscle groups and using cyclical tasks. The key of circuit training is to minimise the rest between stations to ensure the aerobic systems are challenged.

Cardiovascular stations can include wheelchair propulsion, arm ergometry (Figure 9.3), boxing (focus mitts, boxing bag or floor to ceiling ball) or simply repetitive upper limb activities. Whilst arm exercise is not as efficient as leg exercise for cardiovascular fitness improvement, the continuous nature of the exercise will affect aerobic ability. Intensity of wheelchair propulsion can be manipulated by speed or resistance e.g. on a treadmill, up and down inclines or over rough or soft surfaces. If improving wheelchair skills is a goal of the exercise program, they can be incorporated into an obstacle course with wheelchair propulsion e.g. figure eights between two objects or wheeling up and over an obstacle. This gives an extra opportunity for task practise whilst working on cardiovascular fitness. It is also realistic of situations the individual may encounter in their day-to-day life.

In accordance with minimising muscle imbalance, a variety of activities should be used for cardiovascular fitness regardless of the structure of the session. Both forwards and backwards wheelchair propulsion can be used, as can forwards and backwards arm ergometry and different types of boxing.



Arm ergometer in use.

Functional Training and Balance Exercises

Balance and task practise are important parts of improving functional abilities. Although improved cardiovascular fitness and strength will naturally enhance functional performance, the best carry over and functional improvement is seen

when the individual is given the opportunity to practise specific tasks. Balance and functional exercises are designed to practise good movement patterns and control, and not to increase strength and endurance.

At each balance/task practise station, the client should attempt 3 sets of 1 to 3 minutes continuous practise. The number of repetitions the client can complete in this time is irrelevant as movement quality is of the utmost importance. Slow movements require the most stabilising muscle activity and control, thus they are the most useful.

The functional tasks to be included in training will be identified during the initial goal setting session. Appropriate balance exercises will depend largely on the individual's level of injury and their extent of muscle activity. The amount of support provided should be enough to challenge their balance without putting them at risk of falling and sustaining an injury. For example, an individual with a low thoracic injury might be able to sit comfortably on a bench with minimal back support, while someone with a cervical injury will be sufficiently challenged sitting forward in their wheelchair. Individuals with enough lower limb movement can similarly be challenged in standing to improve standing balance. All balance exercises should be completed with a spotter, as most SCI individuals will have slow protective movements and many will be unable to regain balance if they do lose it.

Possible balance exercises are:

- Sitting (with minimal support)
- Sitting on unstable surfaces e.g. duradisc, fitball
- Sitting/standing with eyes closed
- Sitting/standing and moving head and/or arms at different speeds
- Sitting/standing and moving objects in different directions e.g. picking up, transferring hands, putting down somewhere else
- Sitting/standing and throwing and catching objects
- Standing with feet in different positions
- Again, not all of the ideas provided will be suitable for your client(s) or this program, so use your discretion and be specific in your exercise prescription and descriptions.



Long sitting balance in a C5-6 tetraplegic. This requires well managed hamstring and back extensor length in addition to trained trunk balance awareness

Training structure

Warm-up, Cool down and Stretching

A warm-up is used to prepare the body for training and to minimise the risk of injury. A cool down is used to disperse lactic acid build up and minimise delayed onset muscle soreness (DOMS) after training. Gentle arm ergometry or wheelchair propulsion could be used for the warm-up and cool down.

This population typically have tight anterior shoulder musculature due to the heavy bias placed on this area by ADL. These areas therefore, should also be stretched at some point in the session.



Anterior chest and shoulder stretch.

Main Session

Each training session can be structured in one of two ways.

The first is as a circuit, which integrates cardiovascular and resistance/functional exercises, while the second has distinct cardiovascular and exercise sections. The preferred structure will depend on the motivation and fitness of the individual to be trained and the environment in which the training takes place.

Circuit training is one of the best ways to improve both cardiovascular fitness and strength. The different types of activities use both the aerobic and anaerobic systems to produce energy. Rest between exercises should be limited to the time required to move to the next station, and to be physically ready to begin the exercise. By minimising rest periods, the aerobic barrier will be challenged as the individual's heart rate will stay elevated throughout the session. Additionally, the recovery period for a muscle group that has been worked is actually "relative rest", as another area of the body is worked. This allows maximum gains to be made in minimal time. The constant changing of activity also helps to maintain interest, although some individuals may be less compliant with this format as these workouts are often of a higher intensity. Circuit training requires some planning and access to a range of equipment at the appropriate time. Therefore, this form of training may not always be logistically realistic e.g. in a busy gym or if the trainer is not around to set-up or assist at the right time.

The alternate way to structure a session is by dividing the session into separate cardiovascular and resistance/functional exercise components. Ultimately, the time spent on each of these components will be the same as for circuit training, however there will not be the same benefits of alternating the aerobic and anaerobic energy systems, or of minimising the peripheral muscle limitation while maintaining aerobic work. This format may be more realistic in some environments and will be better for particularly unfit clients or individuals who find the idea of exercise intimidating.

Each training session should be approximately 45-50 minutes long. How the session is designed depends upon the aim of the session. If the client is trying to build muscle, they may spend more time doing resistance exercises. If they are trying to improve their aerobic capacity they may spend more time doing continuous low load cyclical activities. It is up to the trainer to design the session, but it suggested approximately 6 resistance exercise/task practise/balance exercise stations and up to 20 minutes of CV activity can be completed in this time period. To

minimise rest periods, the resistance exercise/task practise/balance exercises can be paired e.g. 3 pairs of 2, and the sets of the two exercises alternated.

Two options for physical activity session structure.

Option 1 – Circuit		Option 2 – Steady State	
Warm-up	3 min	Warm-up	3 min
CV	<5 min	CV	<20 min
Exercises 1 and 2 (3 sets alternated)	6 min	Exercises 1 and 2 (3 sets alternated)	6 min
CV	<5 min	Exercises 3 and 4 (3 sets alternated)	6 min
Exercises 3 and 4	6 min	Exercises 5 and 6 (3 sets alternated)	6 min
CV	<5 min	Cool down	3 min
Exercises 5 and 6	6 min	Stretch	5 min
CV	<5 min	Total:	<48 min
Cool down	3 min		
Stretch	5 min		
Total:	<48 min		

The intensity of cardiovascular exercise will be dependent upon the structure of the session. Circuit training will use shorter bursts (3-5 min) of higher intensity exercise (14-17 on the RPE scale) while steady state training will use a longer period (12-20 minutes) of lower intensity exercise (12-13 on the RPE scale). The exact time and intensity will be dependent on each individual's fitness and injury. Individuals with high level injuries have less physiological reserve and may prefer to work at a lower intensity for longer periods.

Guideline for training intensity according to session type/structure.

	Resistance training	CV training	Balance/functional training
Intensity protocol	<ul style="list-style-type: none"> To improve strength and endurance. 8-15RM protocol 8RM load to start. Each session, 3 sets of many as possible with this load until they can do 3x15. Change to new 8RM and repeat. 	<ul style="list-style-type: none"> Intensity is based on the RPE. <p>Circuit</p> <ul style="list-style-type: none"> 4 stations of 3-5 min RPE of 13-15. Optional surge of increased intensity RPE of 16-17. <p>Steady state</p> <ul style="list-style-type: none"> 12-20 minutes of relatively continuous activity RPE of 12-13. 	<ul style="list-style-type: none"> To practise good movement patterns and control. 3 stations of 1-3 min relatively continuous activity. Slow speed to activate stabilizing muscles, number of repetitions is irrelevant.
Mode	<ul style="list-style-type: none"> Free weights Theraband Cable weights Exercise machines <p>Target muscle groups</p> <ul style="list-style-type: none"> Shoulder rotators (external > internal) Shoulder adductors Scapula retractors Shoulder girdle depressors Shoulder extensors > shoulder flexors Elbow extensors Elbow flexors Trunk stabilizers 	<ul style="list-style-type: none"> Arm ergometry Wheelchair propulsion (up inclines or over rough or soft surfaces) Boxing Swinging free weights 	<ul style="list-style-type: none"> Sitting/standing with minimal support +/- Eyes closed +/- Unstable surfaces +/- Head or arm movement +/- Object manipulation
Rest	<ul style="list-style-type: none"> Dependent on the individual, their injury and fitness level. For optimal results, rest between stations should be minimised. Resistance/ functional exercises are paired to provide relative rest for one muscle group while the other is exercised. Recovery time should be increased if the individual reports fatigue that interferes with daily activities. 		

Exercises included in the session are based on the personal goals of each individual, thus each exercise should have a purpose and contribute to the attainment of a particular goal. Due to the high risk of muscle imbalance in this population, each session should aim to work opposing muscle groups evenly. A few different tasks should be used during cardiovascular training, regardless of the structure. Arm ergometry and wheelchair propulsion can be performed in both directions. Most ADL for people with SCI will bias shoulder flexors and scapula

protractors; therefore, these groups should not be overemphasised in resistance training.

The American College of Sports Medicine (ACSM, Durstine, Moore, Painter, & Roberts) recommends that people with SCI should participate in 30 minutes of moderate-intensity physical activity on 5 or more days per week, or at least 20 minutes of vigorous-intensity activity on 3 or more days per week. The program should be designed to be slightly more exerting than their ADLs e.g. wheeling to the shops. Once the client is familiar with the training concepts and the exercises, they may wish to do some training sessions at home using portable equipment such as theraband or free weights. As such, it may be advisable to help the client decide the most suitable time in their daily routine to undertake exercise.

If an individual reports an increase in pain during an exercise or as a result of training, the program should be reviewed. If the problem continues they need to consult their GP or physiotherapist.

Glossary of terms

The terms listed to follow may appear throughout this and associated sites, refer back to here if you require a description or clarification.

Abdominal Binder - Wide elastic binder use to help prevent a drop in blood pressure or used for cosmetic purposes to hold in abdomen. A rigid (non-elastic) binder is used to help empty the bladder in some patients.

ADL - Activities of daily living: eating, dressing, grooming, shaving, etc. Nurses, occupational and physical therapists are the main coaches for ADL, which is sometimes called DLS or daily living skills.

Anaesthesia - Complete loss of feeling.

Anterior - The front of anything. Before or toward the front.

ASIA Score - A measure of function after spinal cord injury, used by physicians. "A" means complete injury; "E" means full recovery.

Autonomic Nervous System - The part of the nervous system that controls involuntary activities, including heart muscle, glands, and smooth muscle tissue. The autonomic nervous system is subdivided into the sympathetic and parasympathetic systems.

Axon - The nerve fiber that carries an impulse from the nerve cell to a target, and also carries materials from the nerve terminals back to the nerve cell. A long, slender part of a neuron that carries the electrochemical signal to another neuron. It's the main or core nerve fiber which generally conducts impulses away from the cell body.

Bilateral - Refers to using both sides of the body or extremities on both sides.

Biofeedback - A process that provides sight or sound information about functions of the body, including blood pressure, muscle tension, etc. The use of sensory feedback to help provide some self-control over autonomic functions, such as blood pressure.

Bradycardia - Slow pulse (< 60 beats per minute)

Brain stem - Composed of midbrain, pons and medulla.

Brown-Sequard Syndrome - An incomplete spinal cord injury where half of the cord has been damaged. The Brown-Sequard syndrome is caused by a functional section of half of the spinal cord. This results in motor loss on the same side as the lesion and sensory loss on the opposite side. This syndrome is very often associated with fairly normal bowel and bladder function and does not prevent the person from being able to walk, although some functional bracing or ambulatory device such as a cane or crutch may be necessary.

Carpal Tunnel Syndrome - A painful disorder in the hand caused by inflammation surrounding the median nerve near the wrist bones.

Catheter - A flexible rubber or plastic tube for withdrawing or introducing fluids into a cavity of the body, usually the bladder.

CT Scan - Computerised axial Tomography is a cross-sectional X-ray enhancement technique that greatly benefits diagnosis with high-resolution video images.

Cauda Equina - A bundle of nerves which branch off the end of the spinal cord and carry messages about bowel, bladder, and sexual function. It is located below the lumbar area of the spinal cord and looks like a horse's tail.

Central Nervous System (CNS) - The CNS includes the brain and spinal cord.

Cerebrospinal Fluid (CSF) - A colourless solution similar to plasma protecting the brain and spinal cord from shock. A lumbar puncture (spinal tap) is used to draw CSF.

Cervical - The neck area, where 8 cervical nerves carry messages for movement and feeling to the arms, the hands, the fingers and the diaphragm.

Complete Lesion - An injury with no motor or sensory function below the area of the spinal cord that was damaged.

Contracture - The stiffening of a body joint secondary to shortened myofascial tissues, to the point that it can no longer be moved through its normal range.

Depression (dysthymia) - An abnormal lowering of mood of psychologic or physiologic origin which is more prolonged than mourning and is time-limited and related to a specific loss.

Dermatome - The area of the skin innervated by the sensory axons with each segmental nerve (root).

Disability - Any restriction or lack (resulting from an impairment) of ability to perform an activity in a manner or within the range considered normal for a human being.

Dorsal Root - The collection of nerves entering the dorsal section (on the back) of a spinal cord segment.

Dura Mater - The outermost of three membranes protecting the brain and spinal cord, it is tough and leather-like. The fibrous outer sheath surrounding the brain and spinal cord.

Dysphagia - Difficulty in swallowing.

Efferent - Motor pathway proceeding from the central nervous system toward the peripheral end organs.

Exacerbation - A recurrence or worsening of symptoms.

Flaccidity - A form of paralysis in which muscles are soft and limp.

Foley Catheter - A rubber tube placed in the urethra, extending to the bladder, in order to empty the bladder. It is held in place with a small fluid-filled balloon.

Guillan Barre Syndrome - A rare illness that affects the spinal nerves as well as the cranial nerves which renders the nerves unable to carry messages for movement, feeling, reflexes, bowel and bladder control.

Halo Traction - The process of immobilising the upper body and cervical spine with a traction device. The device consists of a metal ring around the head, held in place with pins fixed to the skull. A supporting frame is attached to the ring and to a body jacket or vest to provide immobilization.

Harrington Rods - Stainless steel rods placed on the back part of the spinal column during surgery to stabilize thoracic and lumbar injuries.

Hemiparesis - Partial paralysis or loss of movement on one side of the body.

Heterotopic Ossification (HO) - The formation of new bone deposits in the connective tissue surrounding the major joints, primarily the hip and knee. A disorder characterised by the deposition of large quantities of calcium at the site of a bone injury. Often the result of prolonged immobilization. [heterotopic bone].

Hyperreflexia - See "autonomic dysreflexia".

Hyperesthesia - Grossly exaggerated tactile stimuli.

Hypothermia - An extreme lowering of the body temperature. A technique used to cool the spinal cord after injury.

Hypoxia - Lack of blood oxygen due to impaired lung function.

Immune Response - The body's defense function that produces antibodies to foreign antigens. It is important in organ and tissue transplantation since the body is likely to reject new tissues.

Impairment - Any loss or abnormality of psychological, physiological, or anatomical structure or function.

Incomplete Injury - Some sensation or motor control preserved below spinal cord lesion.

Indwelling Catheter - A flexible tube retained in the bladder, used for continuous urinary draining to a leg bag or other device.

Informed Consent - A patient's right to know the risks and benefits of a medical procedure.

Intermittent Catheterisation (ICP) - Using a catheter for emptying the bladder on a regular schedule.

Intrathecal Baclofen - Administration of the anti-spasm drug Baclofen directly to the spinal cord by way of a surgically implanted pump.

Ischemia - A reduction of blood flow that is thought to be a major cause of secondary injury to the brain or spinal cord after trauma.

Lumbar - Lower area of the back. The 5 lumbar nerves carry messages for movement and feeling to the legs and hips.

Motoneuron (motor neuron) - A nerve cell whose cell body is located in the brain and spinal cord and whose axons leave the central nervous system by way of cranial nerves or spinal roots. Motoneuron supply information to muscle. A motor unit is the combination of the motoneuron and the set of muscle fibers it innervates.

Motor Nerve - A nerve which carries messages regarding bodily movement.

MRI (Magnetic Resonance Imaging) - A high-tech diagnostic tool to display tissues unseen in X-rays or by other techniques.

Myelin - A white, fatty insulating material for axons which produced in the peripheral nervous system by Schwann cells, and in the central nervous system by oligodendrocytes. Myelin is necessary for rapid signal transmission along nerve fibers, ten to one hundred times faster than in bare fibers lacking its insulation properties. It insulates axons giving the "white matter" of the central nervous system its characteristic color.

Nerve - Connects the brain and spinal cord with parts of the body; carries messages for movement and feeling.

Nervous System - Includes the brain, spinal cord, and nerves. It controls almost all body functions.

Neurapraxia - The first level of nerve injury. The large motor fibers are predominately affected and anatomic continuity of the nerve is preserved. The prognosis for recovery is excellent and usually complete within a few days to weeks.

Neuron - A nerve cell that can receive and send information by way of synaptic connections consisting of the cell body and extensions of the nerve called axons and dendrites.

Neuropathic / Spinal Cord Pain - Neuropathic (nerve-generated) pain is a problem experienced by SCI patients. A sharp, almost electrical shock, type of pain is the result of damage to the spine and soft tissue surrounding the spine. Phantom limb pain or radiating pain from the level of the lesion is related to the injury or dysfunction at the nerve root or spinal cord.

Neurotmesis - The most severe form of nerve injury. There is complete disruption within the nerve and/or an actual severing of the nerve. This injury needs surgical repair. There is wallerian degeneration of the nerve distal to the site of the injury and the prognosis for recovery is far poorer than in the case of neurapraxia or axonotmesis (the other 2 classes of nerve injuries). A nerve may not always have only one type of injury. It is possible to have combined types of injuries within a given nerve.

Neurotransmitter - A chemical released from a neuron ending, at a synapse, to either excite or inhibit the adjacent neuron or muscle cell. A chemical synthesized within the nerve cell body, characteristic for this type of nerve, and stored at the nerves in pods as granules. Release of these chemicals into the synaptic cleft between axons facilitates nerve transmissions.

Osteoporosis - Loss of bone density, common in immobile bones after SCI.

Paralysis - Complete loss of movement.

Paraplegia - Paraplegia occurs when there is injury to the spinal cord below T1, in the thoracic, lumbar, or sacral area. This causes loss of feeling and movement in the chest, stomach area and legs.

Paraesthesia - Partial loss of feeling.

Paresis - Partial loss of movement.

Peripheral - Nerve tissue not found in the brain or spinal cord.

Peripheral Nervous System - Nerves outside the spinal cord and brain (not part of the central nervous system). If damaged, peripheral nerves have the ability to regenerate.

Plasticity - Long-term adaptive mechanism by which the nervous system restores or modifies itself toward normal levels of function.

Pressure Sore - Also known as decubitus ulcer. A potentially dangerous skin breakdown due to pressure on skin resulting in infection and potential tissue death.

Proprioception - The sense of movement and position.

Quad Cough - A method of helping a patient with tetraplegia cough by applying external pressure to diaphragm, thus increasing the force and clearing the respiratory tract.

Quadriplegia/Tetraplegia - Quadriplegia occurs when there is injury to the spinal cord in the cervical area. This causes loss of feeling and movement in the arms, chest, stomach area and legs.

Range of Motion (ROM) - The normal range of movement of any body joint. Range of Motion also refers to exercises designed to maintain this range and prevent contractures.

Reflex - Movement of a muscle caused by a signal (pain, heat, pressure), that does not come from the brain. It goes from the muscle to the spinal cord and then back to the muscle.

Regeneration - The regrowth of a cell or nerve fiber.

Rehabilitation - Retraining to normal functionality or training for new functionality.

Self-Catheterisation - Intermittent catheterization, the goal of which is to empty the bladder as needed, on one's own, minimizing risk of infection.

Sacrum - The fused sacral vertebrae comprising the lowest part of the back at the base of which the coccyx is joined; includes five nerves which carry messages for movement and feeling to the legs, feet, bowel, bladder, and sexual organs.

Sensation - Touch, pressure, pain and temperature are all body sensations

Sensory Nerve - A nerve which carries feeling (touch, pressure, pain, temperature) messages.

Spasm - An uncontrolled muscle movement.

Spinal Column - The backbone, made up of many sections of bone (vertebrae) stacked one on top of the other. The spinal cord runs down through a canal in the middle of this column.

Spinal Cord - Carries messages about movement and feeling to and from the Brain; contains reflex centers.

Spinal Fluid - Fluid which flows around the brain and spinal cord protecting them from the injury.

Spinal Shock - A period of time when reflexes, movement and feeling are absent below the level of injury.

Subluxation - Complete or partial dislocation (as in shoulder).

Synapse - The specialised junction between a neuron and another neuron or muscle cell for transfer of information such as brain signals, sensory inputs, etc., along the nervous system. These are the junctions between the "sending" fibers of one nerve cell, to the "receiving" fibers of other nerve cells. The axon (sending fiber) ends in multiple branches, each of which has a button-like enlargement that nearly touches the "receiving" fibers of the other nerve cell bodies. Nerve cells "talk" to each other via synapses. Basically the connection between the end of a nerve and the adjacent structure, such as a muscle cell or another nerve ending. Various transmitter chemicals liberated into the synapse make nerve transmissions possible.

Tenodesis - Grip and finger control facilitated by wrist extension.

Tetraplegia - Paralysis affecting the arms, chest, stomach area and legs.

Thoracic - The upper and mid back area, where twelve nerves carry messages for movement and feeling to the mid body.

Urinary Tract Infection (UTI) - Bacterial invasion of the urinary tract, which includes bladder, bladder neck and urethra. Symptoms of UTI include urine that is cloudy, contains sediment and smells foul, and fever. UTI involving the kidneys is

preventable but dangerous. Medications often prescribed for UTI include Keflex, Macrochantin, Furadantin, Septra, Bactim, Mandelamine, penicillin, and amoxicillin. Side effects vary, and may include nausea and vomiting, skin rash or hives.

Vertebrae - Bones which make up the spinal column.

Vital Capacity - The measure of air in a full breath. It is an important consideration for people with high-level tetraplegia who also have impaired pulmonary function.

Vital Signs - Consist of taking blood pressure, pulse, respiration and temperature.

Appendix 6.1 Facility Access Checklist for Fitness Centres



This checklist is designed to assess how accessible a fitness centre is for wheelchair users with no visual or auditory impairment. If the answers to all questions in a section are YES, then that area of the facility is accessible to both manual and motorised wheelchair users. If the answer to some questions is NO, check the barriers/problem/solutions page to see how this limits access to the facility. If major changes are required to make the facility fully accessible, design information can be obtained from the local Council or a disabled access consultant.

PARKING AND STREET ACCESS

	Yes	No
1. Is there an ACROD parking bay at the facility? If NO go to question 6	<input type="checkbox"/>	<input type="checkbox"/>
2. Is the accessible parking bay at least 2.4m wide and 5m long?	<input type="checkbox"/>	<input type="checkbox"/>
3. Is the parking area free of charge? If YES go to question 5	<input type="checkbox"/>	<input type="checkbox"/>
4. Is pay ticket machine accessible to wheelchair users (no kerb, accessible height)?	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there an access aisle from the parking bay to the door of the facility at least 900mm wide?	<input type="checkbox"/>	<input type="checkbox"/>
6. Is the access route from the parking area to the building entrance free of kerbs and steps?	<input type="checkbox"/>	<input type="checkbox"/>
7. Is there an accessible route free of kerbs and steps leading from the street or footpath to the facility entrance?	<input type="checkbox"/>	<input type="checkbox"/>
8. Is the slope on the access route less than 5% (1m rise in 20m run)?	<input type="checkbox"/>	<input type="checkbox"/>

ENTRANCE AREA

	Yes	No
1. Does the entrance door have a clear width of 810mm or more?	<input type="checkbox"/>	<input type="checkbox"/>
2. Can entrance door be opened without knobs or handles that require grasping or twisting?	<input type="checkbox"/>	<input type="checkbox"/>
3. If there is more than one door to the facility do all doors swing in the same direction?	<input type="checkbox"/>	<input type="checkbox"/>
4. Is the access route to reception area free of steps? If YES go to question 6	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there an accessible ramp adjacent to the steps (slope as before, with landings if the ramp changes direction)?	<input type="checkbox"/>	<input type="checkbox"/>
6. Is the facility all on one floor level? If YES go to next section.	<input type="checkbox"/>	<input type="checkbox"/>
7. Are there lifts in the facility?	<input type="checkbox"/>	<input type="checkbox"/>
8. Are lifts in an accessible path of travel with a 1.5m turning area in front of lift?	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the lift door clear width at least 900mm?	<input type="checkbox"/>	<input type="checkbox"/>

EXERCISE EQUIPMENT ACCESS

	Yes	No
1. Is the exercise area wheelchair accessible (access clear width > 810 mm, level surface)?	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there a path of access of 900mm width to each type of equipment used by individuals in a wheelchair, with an area between rows with a 1.5m turning radius ?	<input type="checkbox"/>	<input type="checkbox"/>
3. Are paths around equipment free of obstacles?	<input type="checkbox"/>	<input type="checkbox"/>
4. Is flooring surface non-slip?	<input type="checkbox"/>	<input type="checkbox"/>

LOCKERS AND SHOWERS		
	Yes	No
1. Does facility have a locker room? If NO go to question 4	<input type="checkbox"/>	<input type="checkbox"/>
2. Are there wheelchair accessible doors to the locker room (clear width >810mm, no grasping/twisting of handle required)?	<input type="checkbox"/>	<input type="checkbox"/>
3. Is the path to the lockers 900mm wide?	<input type="checkbox"/>	<input type="checkbox"/>
4. Are there wheelchair accessible doors to the shower area (clear width >810mm, no grasping/twisting of handle required)?	<input type="checkbox"/>	<input type="checkbox"/>
5. Does the shower cubicle have a clear width of at least 900mm?	<input type="checkbox"/>	<input type="checkbox"/>
6. Can water temperature be adjusted before entering shower?	<input type="checkbox"/>	<input type="checkbox"/>
7. Is there a shower bench or shower chair available?	<input type="checkbox"/>	<input type="checkbox"/>
8. Are there grab rails on sidewalls 840-920mm above floor and at least 900mm long?	<input type="checkbox"/>	<input type="checkbox"/>

LOCKERS AND SHOWERS		
	Yes	No
1. Does the door to the toilet have a clear width of at least 900mm?	<input type="checkbox"/>	<input type="checkbox"/>
2. Does the toilet door swing towards the outside?	<input type="checkbox"/>	<input type="checkbox"/>
3. Is the toilet stall at least 1.5m wide and 1.5m long?	<input type="checkbox"/>	<input type="checkbox"/>
4. Is the toilet seat 430-480mm above floor?	<input type="checkbox"/>	<input type="checkbox"/>
5. Does closing the toilet door from the inside require twisting/grasping?	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a grab rail on the side wall at least 900mm long and 840-920mm above floor?	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the floor slip resistant?	<input type="checkbox"/>	<input type="checkbox"/>
8. Are towel dispensers/hand driers easy for wheelchair users to reach?	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the sink counter height 850mm or less?	<input type="checkbox"/>	<input type="checkbox"/>
10. Is there knee space at least 480mm deep under the sink?	<input type="checkbox"/>	<input type="checkbox"/>

EQUIPMENT AND AVAILABLE ASSISTIVE DEVICES		
	Yes	No
1. Is there a wheelchair accessible arm crank ergo?	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there a combined arm-leg ergo which is wheelchair accessible?	<input type="checkbox"/>	<input type="checkbox"/>
3. Parallel bars	<input type="checkbox"/>	<input type="checkbox"/>
4. Light hand weights	<input type="checkbox"/>	<input type="checkbox"/>
5. Wrist weights	<input type="checkbox"/>	<input type="checkbox"/>
6. Medicine balls	<input type="checkbox"/>	<input type="checkbox"/>
7. Padded mats	<input type="checkbox"/>	<input type="checkbox"/>
8. Theraband	<input type="checkbox"/>	<input type="checkbox"/>
9. Gloves with velcro (or similar assistive devices) to grip objects	<input type="checkbox"/>	<input type="checkbox"/>

PROFESSIONAL SUPPORT		
	Yes	No
1. Does your facility have a reference book on disability and associated conditions?	<input type="checkbox"/>	<input type="checkbox"/>
2. Do staff members receive training in communicating with and accommodating people with disabilities?	<input type="checkbox"/>	<input type="checkbox"/>
3. Are staff members able to give directions for accessible routes to the facility, including accessible public transport?	<input type="checkbox"/>	<input type="checkbox"/>

POLICIES		
	Yes	No
1. Are complimentary visits allowed for people with disabilities to assess if the facility meets their needs?	<input type="checkbox"/>	<input type="checkbox"/>
2. Are carers allowed to enter for free?	<input type="checkbox"/>	<input type="checkbox"/>
3. Are membership fees pro-rated depending on how much of the facility/equipment/classes is accessible?	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there a list of accessible equipment available for consumers?	<input type="checkbox"/>	<input type="checkbox"/>

**Appendix 6.2
Pre-Training Risk Management Plan**



PRE-TRAINING RISK MANAGEMENT ACTION PLAN

Potential risk identified	Date checked	Problem detected	Risk rating High, Medium, Low	Who will fix the problem	When will it be fixed	Completed
Are fitness instructors trained to work with clients with SCI?						
Are all fitness instructors trained in first-aid?						
Are personal trainers aware of specific medical needs of their SCI clients?						
Are client's medical conditions and health needs documented and readily accessible to all staff?						
Are documented emergency contact numbers for clients accessible to all staff?						
Is an appropriate first aid kit available?						
Do you have an emergency evacuation procedure for clients with special needs (e.g. wheelchair/limited mobility)?						


Are potentially dangerous floor surfaces removed or sign-posted?						
Are changes in floor surface/height (e.g. a step) clearly marked or sign-posted?						
Are barriers or signs put up when floor surface is wet?						
Do you have equipment to clean up spills immediately?						
Is the floor/ carpet in good condition?						
Are walkways regularly inspected to make sure they are free of obstruction?						
Are doormats fixed or have a non-slip backing?						
Are equipment and fixtures free of sharp edges and properly secured?						
Are loose items (eg free weights) stored appropriately?						
Are storage areas at a suitable height and accessible to wheelchairs?						
Are staffs instructed in the need for tidiness and the facility regularly maintained?						

PARKING ACCESS		
BARRIER	PROBLEM FOR WHEELCHAIR USER	SOLUTION
No ACROD bay	Client cannot come to the facility by private car.	Is there an ACROD bay close by with clear footpath access to the facility? Can staff direct clients to this parking bay?
ACROD bay is incorrect size	A wide bay is needed so the rider can transfer into the wheelchair when it is beside the car and the door is open. Cars/taxis with rear lifts need long bays to unload the wheelchair. Cars with rooftop hoists need vertical clearance.	Manual wheelchair users may be able to park in a standard bay. Discuss this with the client. Can 2 standard bays be sectioned off when the client is coming to the facility? Can the size of the ACROD bay be increased?
Pay parking	Ticket machine may not be accessible.	Talk to car park owners re: free ACROD parking.
Steep slope on access route to building	Manual wheelchair users may require assistance.	Client can call ahead to ask for assistance from staff or bring carer/assistant.
Steps from street entrance	Motorised wheelchairs cannot go up steps. Manual wheelchair users may require assistance.	Install a ramp. Ask the client to call ahead and arrange for a staff member to meet them outside to help.
ENTRANCE AREA		
BARRIER	PROBLEM FOR WHEELCHAIR USER	SOLUTION
Doorway too narrow	NO ACCESS.	Is there an alternative entrance e.g. fire exit that could be used?
Threshold >20mm	Motorised chairs may not be able to go over the threshold.	Purchase threshold ramp. Is there an alternative entrance?
Difficult door handle	Users with poor grip strength may not be able to open the door.	Change the handle. Install a push button to alert reception that assistance is required.
No lift in multilevel facility	NO ACCESS.	
Counter too high.	Wheelchair users have nothing to lean on to fill out forms.	Have a clipboard and pen or small table available.




LOCKERS		
BARRIER	PROBLEM FOR WHEELCHAIR USER	SOLUTION
No suitable lockers e.g. too high, client is unable to manipulate the lock.	The client cannot leave valuables.	Provide an alternative place to leave valuables/bag e.g. at reception.
SHOWERS		
BARRIER	PROBLEM FOR WHEELCHAIR USER	SOLUTION
Door to shower area/cubicle too narrow.	NO ACCESS.	Advise the client the shower is not accessible.
Shower fittings not ideal.	Risk of burns/falls.	Advise the client of the current limitations. Replace/install new fittings as required.
No shower chair.	The individual may not be able to shower.	Purchase a shower chair.
TOILETS		
BARRIER	PROBLEM FOR WHEELCHAIR USER	SOLUTION
Door too narrow	NO ACCESS.	Are there any other toilets in the facility that are different? The other gender? Staff toilets? Advise client that toilet is not accessible. Where is the nearest accessible public toilet? Is there an accessible route from the facility?
Toilet stall too small	No room to manoeuvre chair.	Can partitions be moved? Are there any other toilets in the facility that are different? Advise client that toilet is not accessible. Where is the nearest accessible public toilet? Is there an accessible route from the facility?
Slippery floor	Falls risk when transferring from the chair.	Apply a non-slip coating to floor.
No grab rails	Falls risk when transferring from the chair.	Install a grab rail.
Sink height/design incorrect	Risk of skin damage/ poor hygiene.	Is there an alternative water source the client could use? Replace/install new fittings.

EXERCISE EQUIPMENT ACCESS		
BARRIER	PROBLEM FOR WHEELCHAIR USER	SOLUTION
Limited room around the exercise equipment.	Risk of skin damage/falls. Inaccessibility of some equipment.	Rearrange equipment layout. Can other equipment be used to serve the same purpose as the inaccessible equipment e.g. cable machine.
Narrow seats/ limited support when using specific equipment.	Falls risk when transferring onto and using specific equipment.	Will the client be safe to transfer onto and use the equipment if the trainer is there to spot them. Can other equipment be used to serve the same purpose as the unsafe equipment e.g. cable machine.

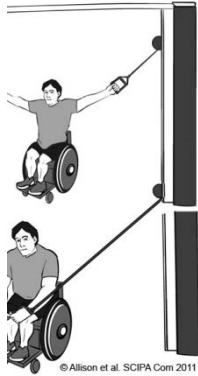
Appendix 6.3 Example of a Physical Activity Program

 TRAIN THE TRAINER	This exercise program is for a specific individual under specific guidance by a Trainer in the T3-SCI program. Not to be used
SPINAL CORD INJURY	
Goal: Improve strength, resistance and balance. Specific Component: Upper limb and trunk muscle capacity	

Participant:	Mr. Smith, C7
Exercise Professional:	

Arm ergometer	Program 1
 <p style="font-size: small; margin-top: 5px;">© Allison et al. SCIPA Com 2011</p>	<p>Target: Improve resistance</p> <p>10x / 1 min bouts of hand cycling to warm-up and improve aerobic capacity. He can cycle forwards and backwards (alternate).</p>
Push-up plus on the wall	
 <p style="font-size: small; margin-top: 5px;">© Allison et al. SCIPA Com 2011</p>	<p>Target: strengthen scapula stabilizers (serratus anterior muscle)</p> <p>3x / 8-10 reps, 1 min rest between sets.</p>
Rowing on cable machine	
 <p style="font-size: small; margin-top: 5px;">© Allison et al. SCIPA Com 2011</p>	<p>Target: strengthen scapula stabilizers (rhomboid muscles)</p> <ul style="list-style-type: none"> It can also be done on the cable machine with flexible handles. Use hand hooks to improve grip ability. <p>3x / 8-10 reps, 1 min rest between sets.</p>
Diagonals from top to bottom	

(unilateral)



Target: strengthen upper limbs – do one arm at a time.

3x / 8-10 reps, 1 min rest between sets.

Diagonals from bottom to top

Place the pulley of the cable machine on the last hole and begin the exercise with your arm across your body (right arm over left leg) and pull the handle (upwards to the right).

Target: strengthen upper limbs – do one arm at a time.

3x / 8-10 reps, 1 min rest between sets.

Shoulder External Rotation

Place the pulley of the cable at the height of your elbow. With elbow at a 90° angle and arm in internal rotation, pull the handle to the side (external rotation).

Target: strengthen external rotators of shoulders (infraspinatus)

3x / 8-10 reps, 1 min rest between sets.

Balance



Target: improve trunk balance

Move arms to the front, up, to the sides, rotate trunk, one arm in front and other back, back to the front and rest.

Repeat 3-5x

END



Target: Improve resistance

10x / 1 min bouts of hand cycling to warm-up and improve aerobic capacity. He cycle forward and backwards (alternate).

Biceps Curl



Target: strengthen biceps.

Check if he has good grip of the weights.

3x / 8-10 reps, 1 min rest between sets.

Rowing on cable machine



Target: strengthen scapula stabilizers (rhomboid muscles)

- It can also be done on the cable machine with flexible handles.

3x / 8-10 reps, 1 min rest between sets.

Shoulder protraction

Position pulley just above shoulder height, have your back to the cable machine, and pull the handles to the front with elbows straight. Perform "puches" without bending the elbows.

Target: strengthen scapula stabilizers (serratus anterior muscle)

3x / 8-10 reps, 1 min rest between sets.

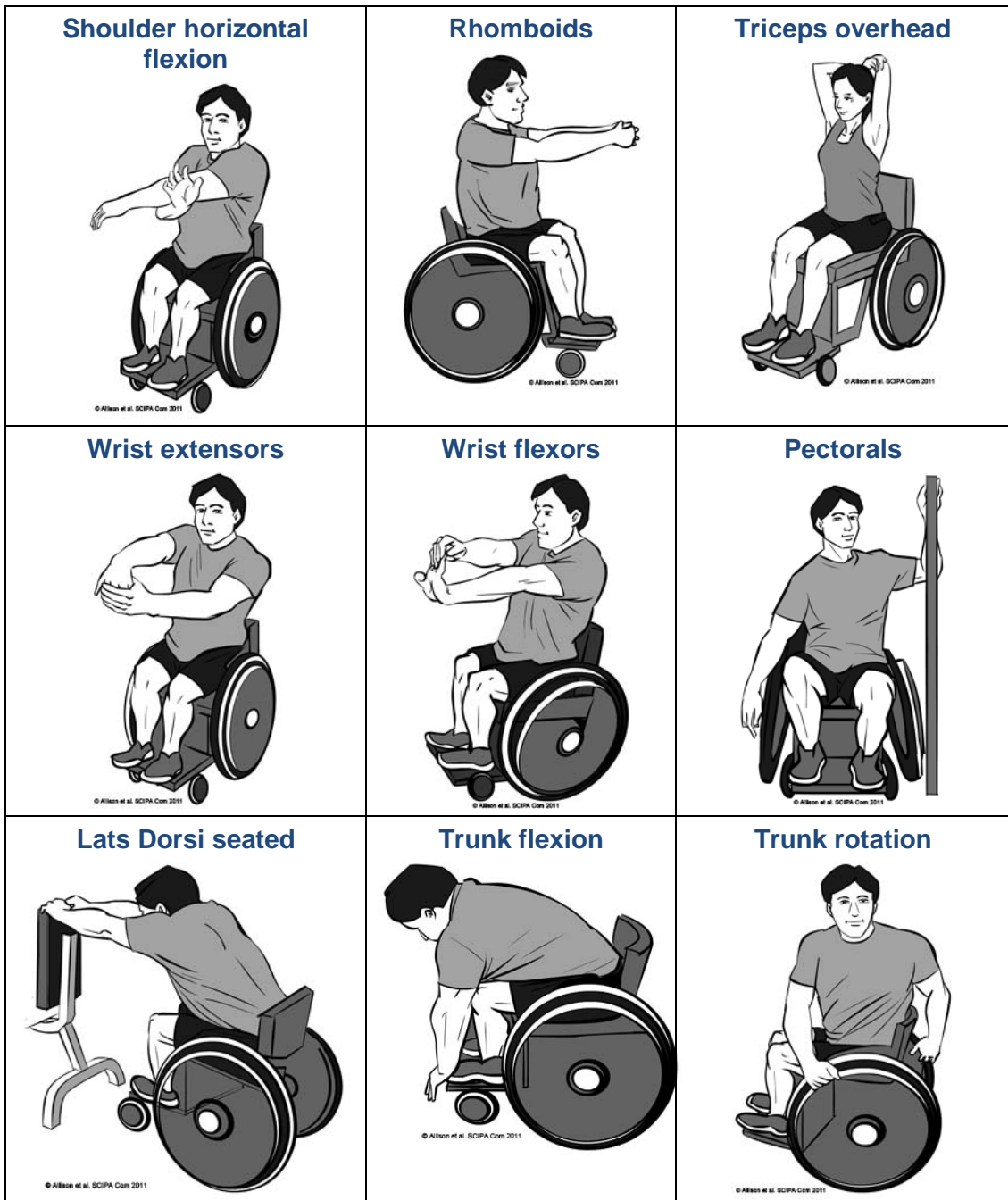
Trunk Diagonals





Hold your hands together and place beside your right knee. "Draw" a diagonal line with your hands in the left upward direction, and take you hands back down to the right. Repeat the same movement on the other side.







Target: improve trunk balance







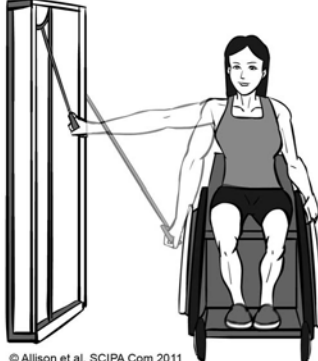
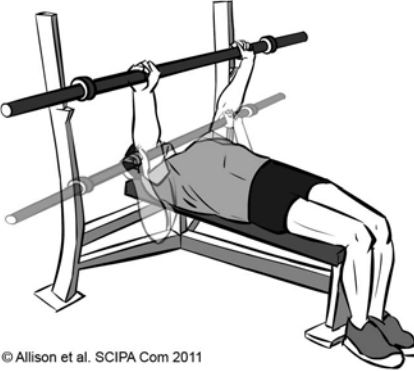




2-3x / 5reps













Appendix 6.4
T3-SCI Exercise Pictures







<p>Arm ergometer</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Boxing Bag</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Partner Boxing</p>  <p>© Allison et al. SCIPA Com 2011</p>
<p>Seated Pushups</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Rolling wheelchair forwards [This can be adapted to specify terrain, incline, distance or other]</p>	<p>Rolling wheelchair backwards [This can be adapted to specify terrain, incline, distance or other]</p>

<p>Bicep Curls free-weights</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Bicep Curls pulleys</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Wrist flexion</p>  <p>© Allison et al. SCIPA Com 2011</p>
<p>Wrist extension</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Shoulder press machine</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Shoulder extension pulley</p>  <p>© Allison et al. SCIPA Com 2011</p>

<p>Shoulder Press free-weights</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Triceps overhead extension</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Triceps kickback</p>  <p>© Allison et al. SCIPA Com 2011</p>
<p>Shoulder flies</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Triceps push-down</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Triceps kickback pulley</p>  <p>© Allison et al. SCIPA Com 2011</p>
<p>Arm Adduction pulleys</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Bench Press Bar</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Pec Deck</p>  <p>© Allison et al. SCIPA Com 2011</p>
<p>Crossover pulleys</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Chest Press narrow</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Chest Press wide</p>  <p>© Allison et al. SCIPA Com 2011</p>

<p>Lats Pull-down</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Lats Pull-down supination</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Lats Pull-down rope</p>  <p>© Allison et al. SCIPA Com 2011</p>
<p>Pull-down overhead</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Single arm row</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Seated Row</p>  <p>© Allison et al. SCIPA Com 2011</p>
<p>Long sitting balance (tetra)</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Seated buttock shifts (fwd)</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Reaching from chair</p>  <p>© Allison et al. SCIPA Com 2011</p>
<p>Object transfer</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Partner boxing</p>  <p>© Allison et al. SCIPA Com 2011</p>	<p>Boxing bag</p>  <p>© Allison et al. SCIPA Com 2011</p>

<p>Seated buttock lifts</p>  <p><small>© Allison et al. SCIPA Com 2011</small></p>	<p>Long sitting triceps dips</p>  <p><small>© Allison et al. SCIPA Com 2011</small></p>	<p>Triceps dips advanced</p>  <p><small>© Allison et al. SCIPA Com 2011</small></p>
<p>Seated elbow extension</p>  <p><small>© Allison et al. SCIPA Com 2011</small></p>	<p>Exercise name:</p>	<p>Exercise name:</p>

Appendix 6.5
T3-SCI Safety Procedures Booklet



Program Coordinator:

Ph:

Email:

Your Node Leader: _____

Ph: _____

Email: _____

This project has been approved by the Curtin University Ethics Approval Committee (approval number HR80/2010). Curtin University Human Research Ethics Committee, Curtin University of Technology, GPO Box U1987, Perth 6845 ph:9266 2784 email:hrec@curtin.edu.au

1. Adverse Event Protocol
2. Injury response
 - a. Loss of consciousness
 - b. Heat Exhaustion
 - c. Skin Damage
 - d. Autonomic Dysreflexia (Hyperreflexia)
 - e. Orthostatic (Postural) Hypertension
 - f. Fractures
 - g. Fall out of wheelchair
3. Pre-Training Risk Management Action Plan **(Unit 6 Assessment 1)**
4. Incident Management **(Forms can be found in resource section, print as many as required)**
 - a. Incident Report Form
 - b. Incident Management Action Plan
5. Client Information **(Forms can be found in resource section)**

If your client experiences a health problem or accident whilst at your facility it is **ESSENTIAL** that the following steps are taken:

1. Apply first-aid (details in FIRST-AID PROCEDURES, this is the responsibility of the fitness trainer who has completed the SCI training program)
2. Call AMBULANCE (000) if necessary
3. Telephone client's emergency contact (details in CLIENT INFORMATION FORM)
4. Complete incident report form as soon as possible and send a copy to Your Node Leader. This is the responsibility of the fitness trainer who has completed the SCI training program.
5. Take steps to prevent a similar incident occurring again (see RISK MANAGEMENT CHECKLIST). This is the responsibility of the trainer who has completed the SCI training program.

SPINAL CORD INJURY – LOSS OF CONSCIOUSNESS

Symptoms

- No response to voice commands/gentle shaking

Possible causes

- Head injury
- Heart problem
- Allergy
- Seizures/convulsions
- Stroke
- Diabetes

Response

1. Apply standard first-aid procedures **D**anger, **R**esponse, **A**irway, **B**reathing, **C**irculation
2. Call AMBULANCE (000)

Symptoms

- Dizziness
- Nausea
- Headache
- Irritability

Response

1. Stop exercising and cool client with water spray/wet cloth/fan
2. Give small sips of cool water to drink
3. Call AMBULANCE (000) if symptoms do not improve after 20 minutes, or if you suspect heat stroke (client collapses or is unconscious)

Symptoms

- Redness or discolouration of skin that does not fade 30 minutes after removing pressure
- Break in skin integrity (eg blister, abrasion)

Response

- If pressure area occurs remove source of problem and advise client to keep pressure off the area and observe carefully over the next few days. If reddening does not resolve or skin breakdown occurs they should consult their MEDICAL PRACTITIONER for treatment
- Small cuts and abrasions should be treated with antiseptic and covered with a sterile dressing. The client should be advised to see their MEDICAL PRACTITIONER if the abrasion covers a large area, the cut is deep, the area does not heal properly or signs of infection develop
- Control bleeding by applying direct pressure to the area and elevate if possible. Call AMBULANCE (000) for severe bleeding

Symptoms

- Pounding headache
- Bradycardia (slowing of heart rate)
- Heavy sweating
- Flushed/reddened skin above the level of SCI
- Goosebumps
- Blurred/spotty vision
- Stuffy nose
- Anxiety
- Chest tightness, heart flutters
- Breathing difficulties

Response

Prompt action is essential. Follow the action response plan as detailed below.

1. Sit upright

Sit the client upright and lower the legs if possible. The client must remain upright until their blood pressure returns to normal. Never lie them down as this may increase their blood pressure further.

2. Loosen clothing

Loosen or take off any tight

- clothing
- shoes or leg braces
- leg bag strap
- external catheter tape
- abdominal binders
- support stockings or bandages

3. Bladder

Check for bladder problems

- Intermittent/external catheter – ask the patient or their carer to empty their bladder using a clean catheter/lubricant. If the bladder cannot be emptied (no catheter or problems with insertion) call for an ambulance. If the bladder empties but blood pressure remains high call for an ambulance.
- Indwelling catheter – Check tubing for kinks or twists and fix them. Empty drainage bag. If there is no urine flow the client should irrigate bladder with a small amount of saline or insert

another catheter. If a catheter cannot be inserted or if symptoms persist call an ambulance

4. Skin

Check the desensitised limbs for skin injury e.g. skin pinched between weights, friction burns, cuts. Remove the problem e.g. the pressure and address any injuries if possible. If the client has sustained an injury, their blood pressure may not decrease automatically. Call an ambulance if symptoms persist as they may require antihypertensive medication.

5. Ambulance

If the symptoms of autonomic dysreflexia continue after the above steps have been taken, call for an ambulance. Tell the paramedics that it is a possible episode of autonomic dysreflexia, suggest that the blood pressure is checked immediately and the patient remains sitting up as long as the blood pressure is high. Remember, many health professionals are not familiar with this condition.

SPINAL CORD INJURY – ORTHOSTATIC HYPOTENSION**Symptoms**

- Dizziness/fainting on changing body position
- Decreased blood pressure

Response

1. Lower the head to increase blood flow to it, this can be done by tilting the wheelchair back so that there is no danger of client falling forwards out of the chair
2. Keep head lowered until dizziness stops
3. Call AMBULANCE (000) if symptoms persist

Symptoms

- Redness, swelling, extensive bruising
- Abnormal limb movement/position
- Increased spasm
- Broken bone sticks out through skin

Response

1. Support the break with padding/splints and immobilise limb
2. Control bleeding with gentle pressure
3. Call AMBULANCE (000)

SPINAL CORD INJURY – FALL FROM WHEELCHAIR

If a wheelchair user falls out of their chair check for any injuries and apply first-aid before returning them to the wheelchair. Let the wheelchair user know how you intend to transfer them back into their chair before you start the manoeuvre, this will allow them to prepare and to warn you of any problems you may encounter.

SCOOP (preferred for manual wheelchair)

This manoeuvre can be performed by one person if the wheelchair user is significantly lighter than the person assisting, otherwise use two assistants to bring the wheelchair upright.

- Unlock the brakes of the wheelchair and tip it onto its back with the push handles on the floor
- Lie the client on their back with their knees and hips flexed so that their knees rest on their chest (ask client to hold knees in position if possible)
- Rock the client's knees and lift their buttocks with one hand. Use your other hand to pull the chair back under the client's buttocks and back. Place the client's legs over the front edge of the seat and assist them to slide into the seat.
- Lock wheelchair brakes
- Come behind the wheelchair, squat down, slide your arms under the client's shoulders and grab the push handles
- Keeping your body close to the chair tip the chair upright onto all four wheels using leg strength for lifting
- As the chair becomes upright use one hand to hold onto the client's shoulders to make sure they do not fall forward

TWO PERSON LIFT (electric wheelchair)

One person controls the legs and the other the body.

- Bring the chair close to the side of the client and lock the wheelchair brakes
- One person grasps the legs as close to the hips as possible, the other person comes behind the client and wraps their arms under the shoulders and around the client's chest. Both assistants should be in a squat position
- Both helpers should lift at the same time on the count of three

- Place the client in the chair taking care not to drag them over the wheelchair tyre or arm rest
- When lifting or lowering the helpers should keep their back straight and use their legs to lift

Appendix 7

SCIPA Com: A Model of Health Promotion and Community Integration

The Spinal Cord Injury and Physical Activity in the Community (SCIPA Com) program is a public health promotion model comprised of the following steps:

1. Development of an educational instrument in the online and hard-copy formats aimed at exercise professionals on training people with spinal cord injury (SCI): *Train the Trainers Spinal Cord Injury Program (T3-SCI®)*.
2. Accreditation of *T3-SCI®* with the national representative body of exercise professionals to offer continuous education point towards their re-registrations requirements every two year. *T3-SCI®* was accredited by *Fitness Australia* and *Register of Exercise Professionals* in New Zealand.
3. Implementation of an organised referral system. Collaborations between the SCI organisations (Australian Quadriplegic Association, Escare, Independence Australia, Paraplegic Benefit Fund, Spinal Cord Injury Network, Spinal Hub, and Wheelchair Sports Association WA) and spinal units (Royal Perth Hospital and Austin Hospital). These links were established to refer out-patients to the SCIPA Com manager. Individuals with SCI were either informed about SCIPA through the organisations' liaison officers or via advertisements in newsletter and emails.
4. Identification of community fitness centres in proximity of the homes of subjects with SCI. The SCIPA Com manager investigated the location and infrastructure of community fitness centres and, if deemed accessible, contacted the manager of the facility.
5. Recruitment of exercise professionals from centres interested in developing knowledge and skills in working with people with SCI.

6. Training and assessment of exercise professionals' knowledge on SCI, risk management, and physical activity training through SCIPA Com's T3-SCI@ via two methods: online learning (with 10 hours of associated study) or through a five hour presential course with another five hours of associated assignments to complete in their own time. Exercise professionals were assessed online through flexible delivery questions or in person with paper based exams. The content delivered was the same in both circumstances. Exercise professionals were required to satisfy an overall 80% of correct answers to qualify for the intervention part of the study.
7. Arrangement of exercise professionals for clients with SCI according to the most convenient geographical location of fitness centres and accessibility. Occasionally, one exercise professional was matched with more than one participant with SCI to satisfy the demand.
8. Stratification of participants with SCI into two groups according to baseline levels of physical activity: Active Group and Inactive Group. The criteria adopted to determine a subject's level of physical activity was based on the recommendations established by the American College of Sports Medicine in order to promote and maintain health. The ACSM states that "all healthy adults aged 18 to 65 years need moderate-intensity aerobic (endurance) physical activity for a minimum of 30 min on five days each week or vigorous-intensity aerobic physical activity for a minimum of 20 min on three days each week. Combinations of moderate- and vigorous-intensity activity can be performed to meet this recommendation."(Haskell et al., 2007) Participants with reports over two and a half hours per week of moderate-intensity aerobic physical activity or more than one hour of vigorous-intensity aerobic physical activity were categorised as physically active and those that did not achieve this threshold were classified as physically inactive
9. Assignment of subjects in the Active Group and Inactive Group with exercise professionals and goal setting for their physical activity program (one to four weeks of planning).
10. Conjoint development of a personalised 8-to-12 week physical activity program between exercise professionals, physiotherapists and clients with SCI prior to the commencement of the physical activity program.

11. Execution of the physical activity program supervised by their assigned exercise professionals twice a week, 30 to 60 minutes a day, for 8-to-12 weeks (according to the participants' availability).
12. Assessment of the two groups (active and inactive) at four different time periods: baseline (recruitment period), at the end of the physical activity program (after 8-to-12 weeks), after three months, and lastly after six months. Baseline assessments involved self-reported demographic characteristics, information on physical activity levels, functional goal achievement, self-esteem and quality of life. Follow-up evaluations analysed changes to these last four outcomes.

**Appendix 8
Physical Activity Recall Assessment (PARA-SCI)**

PARA-SCI RECORDING SHEET

For each activity indicate: 1. Intensity: Mild = Mild, Mod = Moderate, Heavy = Heavy, NAA = nothing at all 2. Duration (min) 3. Type: LA or LTPA

<i>Be sure to record the date!</i>		Day 1: Date:				Day 2: Date:				Day 3: Date:			
		Activity	Intensity	Min	Type	Activity	Intensity	Min	Type	Activity	Intensity	Min	Type
Morning routine	Wake up time												
	Transfer												
	Bowel/bladder management												
	Bathing												
	Personal hygiene												
	Dressing lower body												
	Dressing upper body												
	Other												
Breakfast													
		Activity	Intensity	Min	Type	Activity	Intensity	Min	Type	Activity	Intensity	Min	Type
Morning													

Lunch													
Afternoon													
Dinner													
Evening													
		Activity	Intensity	Min	Type	Activity	Intensity	Min	Type	Activity	Intensity	Min	Type
Evening routine	Bedtime												
	Transfer												
	Bowel/bladder management												
	Bathing												
	Personal hygiene												
	Dressing lower body												
	Dressing upper body												
	Positioning												
	Other												

Time 1		Mild			Moderate			Heavy		
		ADL	LTPA	total	ADL	LTPA	total	ADL	LTPA	total
Day 1	Morning Routine									
	Daytime									
	Evening Routine									
Day 2	Morning Routine									
	Daytime									
	Evening Routine									
Day 3	Morning Routine									
	Daytime									
	Evening Routine									

Appendix 9
World Health Organisation Quality of Life Questionnaire (WHOQOL-BREF)

WORLD HEALTH ORGANIZATION QUALITY OF LIFE BREF SCALE -
WHOQOL-BREF

Please read each question, assess your feelings, and circle the number on the scale that gives the best answer for you for each question.

		<i>(Please circle the number)</i>				
		Very poor	Poor	Neither poor nor good	Good	Very Good
		1	2	3	4	5
1.	How would you rate your quality of life?					
		<i>(Please circle the number)</i>				
		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
		1	2	3	4	5
2.	How satisfied are you with your health?					

The following questions ask about **how much** you have experienced certain things **in the last two weeks**.

		<i>(Please circle the number)</i>				
		Not at all	A little	A moderate amount	Very much	An extreme amount
		1	2	3	4	5
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?					
4.	How much do you need any medical treatment to function in your daily life?					
5.	How much do you enjoy life?					
6.	To what extent do you feel your life to be meaningful?					
7.	How well are you able to concentrate?					
8.	How safe do you feel in your daily life?					
9.	How healthy is your physical environment?					

These questions ask about **how completely** you experience or were able to do certain things **in the last 2 weeks**.

		<i>(Please circle the number)</i>				
		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		<i>(Please circle the number)</i>				
		Very poor	Poor	Neither poor nor well	Well	Very well
15.	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good** or **satisfied** you have felt about various aspects of your life **over the last two weeks**.

		<i>(Please circle the number)</i>				
		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your ADLs?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you	1	2	3	4	5

<i>(Please circle the number)</i>					
Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied	
with your abilities?					
20. How satisfied are you with your personal relationships?	1	2	3	4	5
21. How satisfied are you with your sex life?	1	2	3	4	5
22. How satisfied are you with the support you get from your friends?	1	2	3	4	5
23. How satisfied are you with the conditions of your living place?	1	2	3	4	5
24. How satisfied are you with your access to health services?	1	2	3	4	5
25. How satisfied are you with your mode of transportation?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things **in the last two weeks**.

<i>(Please circle the number)</i>				
Never	Seldom	Quite often	Very often	Always
1	2	3	4	5
26. How often do you have negative feelings, such as blue mood, despair, anxiety, depression?				

Did someone help you to fill out this form?
(Please circle Yes or No)

Yes	No
-----	----

Thank you for your help!

Appendix 10

Fitness Centres Participating in SCIPA Com

Thirty-two venues collaborated with SCPA Com in seven cities:

- Perth (17): Altone Park Leisure Centre, Arena Joondalup Venues West, Bayswater Waves, Belmont Oasis Leisure Centre, Challenge Stadium Venues West, City of Mandurah Recreation Centre (Halls Head), Curtin Stadium, Fitness First Floreat, Leisurepark Balga, Lords Recreation Centre Subiaco, Melville Aquatic Fitness Centre, Snap Fitness Armadale, South Lake Leisure Centre, Stirling Leisure Centre Scarborough, UWA Fitness and Recreation Centre, Wanneroo Aquamotion, YMCA Morley Sport & Recreation Centre;
- Melbourne (7): YMCA (Ashburton Pool & Recreation Centre, Boroondara Sports Complex, Brunswick Baths, Kew Recreation Centre, Knox Leisureworks, North Melbourne Community Centre) and BayFit Leisure Centre;
- Christchurch (3): Anytime Fitness, Mint Fitness, and YMCA Christchurch;
- Cairns: Fitness Form & Function;
- Esperance (2): Bay of Isles Leisure Centre (BOILC) and Fitness Exercise Specialist Professionals (ESP);
- Ballarat: YMCA Ballarat;
- Dunsborough: Perfect Balance Gym & Personal Training.