

**BRIDGING THE GAP FROM INPATIENT REHABILITATION TO  
SUSTAINABLE HEALTH AND WELLNESS IN SPINAL CORD INJURED  
INDIVIDUALS**

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## **DECLARATION OF ORIGINALITY**

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the authorship owner thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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## SUMMARY

**Background:** A spinal cord injury is a devastating and life changing neurological event that present multiple challenges throughout the life of the affected individual. One of the challenges is being physically active and more specifically healthy living. Physical activity has many benefits and plays an essential role in community reintegration, which is considered the final outcome of the rehabilitation process. In South Africa this outcome is seldom achieved due to the lack of physical activity opportunities. Without regular physical activity the physical gains that were achieved in hospital are easily diminished or lost and this is a major concern as it ultimately affects health and wellness. **Objective:** To determine the barriers and facilitators to physical activity and whether an intervention designed to reduce the barriers can be successful in promoting health and wellness in people with a spinal cord injury. **Design:** An experimental research design incorporating both quantitative and qualitative methodologies was used to execute the study. **Methods:** A self-developed research questionnaire was distributed to people with a spinal cord injury in the Western Cape, South Africa in order to identify the barriers to physical activity. The results from the research questionnaire were used to design a 16 week intervention which was implemented in two different environments (formal exercise setting and community based setting) and its success was measured by physical tests, the reintegration to normal living index questionnaire and the research questionnaire. **Subjects:** Fifty seven people with a spinal cord injury completed the research questionnaire and 16 participants partook in the intervention. **Results:** In the beginning (pre-intervention) the most important barriers were the environmental barriers and included problems with accessibility and lack of facilities, lack of transport, and the weather. The most reported facilitators were personal, which included a desire to be active, to improve self esteem and because physical activity made them feel good. Based on the results from the research questionnaire the intervention was implemented and showed that the participants from both groups improved their physical abilities (strength, endurance and functional abilities) and their satisfaction with community participation. The barriers that were identified prior to the intervention were also considerably reduced, especially in the community based group. The participants also agreed that physical activity was beneficial and important and that they would like to stay physically active post-intervention. **Discussion and Conclusion:** People with a spinal cord injury face many barriers in being physically active, however, by reducing the barriers a community based physical activity program can be successful in introducing people with a spinal cord injury to a life of healthy living and wellness. Although some of the environmental and program barriers remained, the personal facilitators that were identified were enough to ensure physical activity adherence.

**Key words:** Physical Activity, Spinal Cord Injury, Barriers, Facilitators, Formal Exercise Setting, Community Setting

## OPSOMMING

**Agtergrond:** 'n Spinaalkoordbesering is 'n verpletterende neurologiese gebeurtenis wat die res van die betrokke individu se lewe ingrypend verander deur veelvuldige uitdagings daar te stel. Een van hierdie uitdagings is hoe om fisies aktief en spesifiek gesond te leef. Fisiese aktiwiteit het verskeie voordele en speel 'n noodsaaklike rol in die herintegrasie by 'n gemeenskap, wat as die einddoel van die rehabilitasieprogram gesien word. In Suid-Afrika word hierdie uitkoms egter selde bereik vanweë 'n gebrek aan geleenthede vir fisiese aktiwiteit. Sonder gereelde fisiese aktiwiteit kan die fisiese vordering wat in die hospitaal behaal is maklik verminder of verloor word; 'n groot besorgdheid aangesien dit gesondheid en welstand affekteer. **Doelwit:** Om die hindernis en fasiliteerders van fisiese aktiwiteit te bepaal, asook om vas te stel of 'n intervensie met die doel om hierdie hindernisse te verminder, kan bydra tot die bevordering van die gesondheid en welstand van persone met 'n spinaalkoordbesering. **Ontwerp:** 'n Eksperimentele navorsingsontwerp wat sowel kwantitatiewe as kwalitatiewe metodes insluit, is vir die ondersoek gebruik. **Metodes:** 'n Vraelys is ontwikkel en aan persone in die Wes-Kaap, Suid-Afrika, wat aan 'n spinaalkoordbesering ly, uitgedeel om die hindernisse tot fisiese aktiwiteit te identifiseer. Die resultate uit hierdie navorsingsvraelys is gebruik om 'n intervensie te ontwerp wat in twee verskillende omgewings geïmplementeer is ('n formele oefeningsituasie en 'n gemeenskapgebaseerde situasie). Die geslaagdheid van die intervensie is getoets deur middel van fisiese toetse, die vraelys wat herintegrasie in normale leefstyl toets, asook die navorsingsvraelys. **Subjekte:** Sewe-en-vyftig mense met 'n spinaalkoordbesering het die vraelys ingevul en 16 deelnemers het aan die intervensie deelgeneem. **Resultate:** Voor die intervensie was die belangrikste hindernisse die omgewingshindernisse wat toeganklikheid en gebrekkige fasiliteite en vervoer, asook die weer, ingesluit het. Die fasiliteerders wat die meeste aangedui is, was persoonlik, insluitende die behoefte om aktief te wees, om die selfbeeld op te bou en om goed te voel as gevolg van oefening. Op grond van hierdie resultate is die intervensie geïmplementeer en is aangetoon dat deelnemers vanuit beide groepe sowel hul fisiese vermoëns en hul bevrediging uit gemeenskapsdeelname verbeter het. Die hindernisse wat voor die intervensie aangedui is, is ook aansienlik verminder, veral in die gemeenskapsgebaseerde groep. Die deelnemers het saamgestem dat fisiese aktiwiteit definitief voordelig en belangrik is en dat hulle na afloop van die intervensie fisies aktief sou wou bly. **Bespreking en gevolgtrekking:** Mense met 'n spinaalkoordbesering staar verskeie hindernisse in die gesig wanneer dit kom by fisiese aktiwiteit, maar deur die hindernisse in 'n gemeenskapsgebaseerde aktiwiteitsprogram te verminder kan mense met 'n spinaalkoordbesering gehelp word om weer aan 'n lewe van gesondwees en welstand voorgestel word. Hoewel sekere omgewings- en ander programbeperkings bly staan het, is

die persoonlike fasiliteerders wat geïdentifiseer is, genoeg om te verseker dat daar vorentoe by fisiese aktiwiteit gehou word.

**Sleutelwoorde:** fisiese aktiwiteit, spinaalkoordbesering, hindernisse, fasiliteerders, formele oefeningsituasie, gemeenskapsituasie

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## TABLE OF CONTENTS

CHAPTER 1 INTRODUCTION.....	1
1.1. Introductory Orientation .....	1
1.2. Background to the Study.....	2
1.2.1. Disability and Exclusion .....	2
1.2.2. Physical Activity Levels in People with a Spinal Cord Injury .....	4
1.2.3. Physical Activity Opportunities for Persons with a Spinal Cord Injury .....	6
1.3. Problem Statement .....	7
1.3.1. The role of a Biokineticist.....	7
1.3.2. The Significance of the Research to the South African Department of Health ..	8
1.4. Scope of the Study.....	9
1.5. Assumptions .....	9
1.5.1. Phase I: Pilot Study and Research Questionnaire.....	9
1.5.2. Phase II: Intervention .....	9
1.6. Purpose of the Study .....	9
1.7. Aim and Objectives .....	10
1.8. Research Questions .....	10
1.9. Key Terminology.....	11
1.9.1. Activities of Daily Living (ADL) .....	11
1.9.2. Barrier.....	11
1.9.3. Community Based Setting.....	11
1.9.4. Community Reintegration.....	11
1.9.5. Disability .....	11
1.9.6. Exercise.....	12
1.9.7. Facilitator .....	12
1.9.8. Formal Exercise Setting.....	12
1.9.9. Health and Wellness .....	12
1.9.1. Physical Activity .....	12
1.9.1. Physical Fitness.....	12
1.9.2. Rehabilitation .....	12
1.9.3. Spinal Cord Injury (SCI).....	13
1.10. Outline of Chapters .....	13
CHAPTER 2 THE GREAT DIVIDE.....	14
2.1. Chapter Overview .....	14
2.1.1. A Brief History.....	14
2.2. The Spinal Cord and Spinal Cord Injury.....	15



2.2.1.	Aetiology and Incidence Rate .....	18
2.2.2.	Stages of Rehabilitation and Secondary Complications after a SCI .....	19
2.3.	Secondary Complications .....	24
2.3.1.	Rehospitalisation .....	30
2.4.	Quality of Life and Physical Activity within SCI patients .....	33
2.4.1.	Quality of Life.....	33
2.4.2.	Quality of Life and Measurement of Quality of Life.....	34
2.4.3.	Community Participation and Reintegration .....	35
2.4.4.	Physical Activity .....	38
2.4.5.	Physical Activity and Exercise Recommendations .....	41
2.5.	The Effects of a SCI on Physical Activity.....	43
2.5.1.	Autonomic Function .....	43
2.5.2.	Physical Capacity .....	44
2.5.3.	Muscle Strength.....	48
2.5.4.	Balance and Flexibility (Range of Motion) Training .....	49
2.5.5.	Alternative Therapies that can Improve Functional Ability in PWaSCI.....	51
2.6.	The Great Divide.....	52
2.6.1.	Facilitators and Barriers to Physical Activity.....	54
2.6.2.	Facilitators to Physical Activity .....	54
2.6.3.	Barriers to Physical Activity.....	57
2.7.	Community Based Health and Wellness .....	62
2.8.	Improving Physical Activity Behaviour after Rehabilitation within South Africa .....	66
2.9.	Summary .....	69
CHAPTER 3 METHODOLOGY .....		70
3.1.	Introduction .....	70
3.2.	Research Approach .....	70
3.3.	Research Setting .....	70
3.3.1.	Study Population.....	71
3.3.2.	Participant Selection .....	71
	Inclusion Criteria .....	71
	Exclusion Criteria .....	71
3.4.	Statistical Analysis .....	72
3.4.1.	Phase I: Research Questionnaire .....	72
3.4.2.	Phase II: The Intervention .....	72
3.5.	Ethical Aspects .....	73
3.5.1.	Ethical Considerations .....	73
3.6.	Schematic layout of Research Design Phase I and Phase II.....	75

3.7.	Methods Phase I: Determining the Barriers and Facilitators .....	76
3.7.1.	Timeline for Executing the Methods .....	76
3.7.2.	Research Design and Data Collection Method .....	77
3.7.3.	The Pilot Study .....	79
3.7.4.	Research Questionnaire .....	79
3.8.	Methods Phase II: Removing the Barriers to Physical Activity.....	80
3.8.1.	Research Design and Data Collection Method.....	80
3.8.2.	The Intervention.....	80
3.8.3.	Training Environment Selection .....	80
	Inclusion Criteria: .....	80
3.8.4.	Volunteer Recruitment and Training.....	82
	CVW Inclusion Criteria .....	82
3.8.5.	Intervention: Implementing the Exercise Activity Program.....	84
3.9.	Procedures and measurements .....	86
3.9.1.	Physical Test Battery .....	86
3.9.2.	Questionnaires.....	86
3.9.3.	Exercise Program .....	86
3.9.4.	Outcome Variables during the Tests and Exercise Sessions .....	88
3.9.5.	Data Collection Procedures .....	93
	CHAPTER 4 RESULTS AND DISCUSSION PHASE I .....	94
4.1.	Introduction.....	94
4.2.	Socio Demographic and Injury Profile .....	94
4.3.	Barriers to Physical Activity Participation .....	95
4.3.1.	Personal Barriers .....	96
4.3.2.	Environmental Barriers .....	97
4.3.3.	Social Barriers .....	97
4.4.	Facilitators to Physical Activity Participation Identified by Persons with a Spinal Cord Injury.....	98
4.4.1.	Personal Facilitators .....	99
4.4.2.	Environmental Facilitators.....	99
4.4.3.	Social Facilitators.....	100
4.4.4.	Program/Policy Facilitators .....	100
4.5.	Phase I Discussion .....	101
4.5.1.	Socio Demographic and Injury Profile .....	101
4.5.2.	Barriers .....	103
4.5.3.	Facilitators .....	106
	CHAPTER 5 RESULTS AND DISCUSSION: PHASE II .....	110

5.1.	Introduction .....	110
5.2.	Socio-Demographic and Injury Profile of the Participants.....	110
5.3.	Results: Impact of Physical Activity on Physical Abilities and mRNLI Over Time	113
5.3.1.	Modified Return to Normal Living Index (mRNLI) .....	113
5.3.2.	Manual Muscle Test (MMT) .....	114
5.3.3.	12-min-Push Test (12min PT).....	116
5.3.4.	One-Stroke-Push Task (1 stroke PT) .....	117
5.3.5.	Forward-Vertical-Reach Test (Fwd VRT) .....	119
5.4.	Discussion: Impact of Physical Activity Program on Physical Abilities and mRNLI Over Time .....	120
5.4.1.	Modified Reintegration to Normal Living Index .....	120
5.4.2.	Manual Muscle Test.....	121
5.4.3.	12 min-Push Test.....	122
5.4.4.	One-Stroke-Push Task .....	123
5.4.5.	Forward-Vertical-Reach Test .....	124
5.4.6.	Conclusion .....	124
5.5.	Results: Change in Barriers and Facilitators over Time.....	125
5.5.1.	Barriers Reported by the Participants .....	126
5.5.2.	Personal Barriers .....	127
5.5.3.	Environmental Barriers .....	129
5.5.4.	Social Barriers .....	131
5.5.5.	Program/Policy Barriers .....	133
5.5.6.	Facilitators Reported by the Participants.....	135
5.5.7.	Personal Facilitators .....	136
5.5.8.	Environmental Facilitators.....	138
5.5.9.	Social Facilitators.....	140
5.5.10.	Program/Policy Facilitators .....	142
5.5.11.	Conclusion of the Results .....	144
5.6.	Discussion: Change in Barriers over Time .....	144
5.6.1.	Personal Barriers .....	146
5.6.2.	Environmental Barriers .....	148
5.6.3.	Social Barriers .....	150
5.6.4.	Program/Policy Barriers .....	150
5.6.5.	Conclusion .....	152
5.7.	Discussion: Change in Facilitators over Time.....	152
5.7.1.	Personal Facilitators .....	152
5.7.2.	Environmental Facilitators.....	153

5.7.3. Social Facilitators.....	153
5.7.4. Program/Policy Facilitators .....	154
5.7.5. Conclusion.....	155
CHAPTER 6 CONCLUSIONS AND RECOMMENDATIONS.....	156
6.1. Introduction.....	156
6.2. Conclusion.....	161
6.3. Summary of Practical Implications .....	162
6.4. Limitations to the Study.....	162
6.5. Recommendations for Future Research.....	164
REFERENCES .....	165

## LIST OF TABLES

Table 1: Functional outcomes for cervical lesions .....	16
Table 2: Functional outcomes for thoracic and lumbar spine (Adapted from Kirshblum <i>et al.</i> , 2007:63) .....	18
Table 3: Spinal cord injury incidence rates .....	19
Table 4: Stages of rehabilitation (Fekete and Rauch, 2012).....	20
Table 5: Secondary Conditions: Pressure Ulcers, Urinary and Respiratory conditions .....	25
Table 6: Secondary conditions: Chronic pain, fatigue and depression.....	26
Table 7: Secondary conditions: Musculoskeletal injuries.....	27
Table 8: Rehospitalsations due to secondary conditions .....	31
Table 9: ACSM (2013) exercise recommendations for able bodied individuals.....	41
Table 10: Ginis et al. (2011) exercise recommendations for persons with a SCI .....	42
Table 11: Physical capacity norms for men with tetraplegia (TP), paraplegia (PP) (Janssen <i>et al.</i> , 2002) and able-bodied men (AB) (Heyward, 2010).....	47
Table 12: Facilitators to physical activity and exercise .....	55
Table 13: Barriers to physical activity and exercise .....	57
Table 14: Theories to improve physical activity behaviour.....	67
Table 15: The advantages and disadvantages of using a questionnaire to collect data (Libweb, nd).....	78
Table 16: The basic layout of the exercise program .....	87
Table 17: Periodization of the physical activity program .....	88
Table 18: How to administer the 12 min-Push Test (Vanderthommen <i>et al.</i> , 2002) .....	92
Table 19: Guidelines for interpreting test results (Vanderthommen <i>et al.</i> , 2002).....	92
Table 20: The socio-demographic and injury profile of persons with a spinal cord injury .....	95
Table 21: Prevalence of personal barriers to physical activity .....	96
Table 22: Prevalence of environmental barriers to physical activity.....	97
Table 23: Prevalence of social barriers to physical activity.....	97
Table 24: Prevalence of program/policy barriers to physical activity .....	98
Table 25: Prevalence of personal facilitators to physical activity .....	99
Table 26: Prevalence of environmental facilitators to physical activity.....	100
Table 27: Prevalence of social facilitators to physical activity .....	100
Table 28: prevalence of program/policy facilitators to physical activity .....	101
Table 29: Institute for Security Services (ISS) crime hub statistics (2013/2014) South Africa .....	108
Table 30: Participant socio-demographic and injury profile .....	111
Table 31: Reasons for participant drop-out from the PA program.....	112

Table 32: Participant adherence rate to the PA program.....	112
Table 33: mRNL Index at baseline and post-intervention in the Community and WCRC groups (VAS 4 point ordinal scale).....	114
Table 34: Manual muscle test results (Grade 0-5).....	115
Table 35: 12-min-push test results (m).....	117
Table 36: One-Stroke-Push Task Results (cm) .....	118
Table 37: Forward-vertical-reach test results (cm) .....	119
Table 38: Percentage change in the number of barriers and facilitators as reported by the participants at pre-intervention and two and six months post-intervention .....	126
Table 39: Change in personal barriers over time for the different environments .....	128
Table 40: Change in environmental barriers over time for the different environments .....	130
Table 41: Change in social barriers over time for the different environments .....	132
Table 42: Change in program/policy barriers over time for the different environments .....	134
Table 43: Change in personal facilitators over time for the different environments .....	137
Table 44: Change in environmental facilitators over time for the different environments ...	139
Table 45: Change in social facilitators over time for the different environments.....	141
Table 46: Change in program/policy facilitators over time for the different environments ..	143

## LIST OF FIGURES

Figure 1: Rec Tech RAMP model (Rimmer <i>et al.</i> , 2008).....	62
Figure 2: Theory of Planned Behaviour Process .....	68
Figure 3: Schematic representation of the study .....	75
Figure 4: Timeline for executing the methods.....	76
Figure 5a and 5b: WCRC facility and equipment.....	81
Figure 6a and 6b: Macassar Community facility .....	81
Figure 7a and 7b: Strand Community facility and equipment.....	82
Figure 8: Hand straps for Tetraplegics .....	84
Figure 9: Program exercises .....	84
Figure 10: Periodization of the exercise program .....	87
Figure 11: Prevalence of barriers to physical activity.....	96
Figure 12: Prevalence of facilitators to physical activity.....	99
Figure 13: Percentage change in mRNLI in the Community and WCRC group from baseline over time .....	114
Figure 14: Percentage change in MMT in the Community and WCRC groups from baseline over time .....	116
Figure 15: Percentage change in 12min-push-test in the Community and WCRC group from baseline over time.....	117
Figure 16: Percentage change in the one-stroke-push task in the Community and WCRC group from baseline over time.....	118
Figure 17: Forward-vertical-reach test % change from baseline.....	119
Figure 18: Reduction in the number of barriers (%) in the WCRC group from baseline over time.....	127
Figure 19: Reduction in the number of barriers (%) in the Community group from baseline over time .....	127
Figure 20: The change in total barriers over time between the two groups.....	129
Figure 21: The change in total barriers over time between the two groups.....	131
Figure 22: The change in total barriers over time between the two groups.....	132
Figure 23: The change in total barriers over time between the two groups.....	135
Figure 24: % Facilitator reduction in the WCRC group over time.....	136
Figure 25: % Facilitator reduction in the Community group over time.....	136
Figure 26: The change over time in the total personal facilitators identified by the participants from both groups.....	138
Figure 27: The change over time in the total environmental facilitators identified by the participants from both groups.....	140

Figure 28: The change over time in the total social facilitators identified by the participants from both groups.....	142
Figure 29: The change over time in the total program/policy facilitators identified by the participants from both groups.....	144



## LIST OF APPENDICES

APPENDIX A: RESEARCH QUESTIONNAIRE.....	186
APPENDIX B: INFORMED CONSENT .....	195
APPENDIX C: PHYSICAL ACTIVITY READINESS QUESTIONNAIRE (PAR Q AND YOU) .....	200
APPENDIX D: BORG RATE OF PERCEIVED EXERTION (RPE).....	201
APPENDIX E: 12 MIN PUSH TEST .....	202
APPENDIX F: ONE STROKE PUSH TASK .....	204
APPENDIX G: FORWARD VERTICAL REACH TEST .....	205
APPENDIX H: MANUAL MUSCLE TESTING (MMT).....	206
APPENDIX I: REINTEGRATION TO NORMAL LIVING INDEX (RNLI).....	208
APPENDIX J: TRAINING PROGRAM OUTLINE FOR THE VOLUNTEERS .....	210
APPENDIX K: BASIC SCREENING QUESTIONS AND PHYSICAL ACTIVITY PROGRAM .....	215
APPENDIX L: INJURY PROTOCOL .....	217
APPENDIX M: ACCEPTANCE LETTERS FROM SENECIO AND WESTERN CAPE REHABILITATION CENTRE .....	218

## **LIST OF ABBREVIATIONS**

1 stroke PT: One Stroke Push Task

12min PT: 12minute Push Test

ADL: Activities of Daily Living

DOMS: Delayed Onset Muscle Soreness

Fwd VR: Forward Vertical Reach Test

MMT: Manual Muscle Test

mRNLI: Modified Reintegration to Normal Living Index

MVA: Motor Vehicle Accidents

PA: Physical Activity

PAR Q and YOU: Physical Activity Readiness Questionnaire and YOU

PWaSCI: People/person with a Spinal Cord Injury

PWD: Person with a Disability

QOL: Quality of Life

RNLI: Reintegration to Normal Living Index

SCI: Spinal Cord Injury

TB: Tuberculosis

TBP: Theory of Planned Behaviour

VO<sub>2</sub>R: VO<sub>2</sub> Reserve

WCRC: Western Cape Rehabilitation Centre

## CHAPTER 1

### INTRODUCTION

#### 1.1. Introductory Orientation

A spinal cord injury (SCI) is a devastating and life changing neurological event that impacts many facets of life, including the patient, family, and caregivers (LiVecchi, 2011; Mothabeng, 2011). People with an acquired disability such as a SCI experience multiple challenges throughout their lives (Anderson, 2004), especially during the initial stages of the rehabilitation process. They therefore require a supportive environment that can guide them while they adapt to their lives with a disability. In the final phase of rehabilitation the process of community reintegration sometimes seems insurmountable, especially in developing countries where specific psychosocial challenges are experienced (Richardson, Papathomas, Smith and Goosey-Tolfrey, 2015). Some of these challenges include cultural stigmas, poverty and lack of infrastructure, particularly in rural areas (Richardson, Papathomas, Smith and Goosey-Tolfrey, 2015). Although not much research has been conducted to determine PA levels in people with a disability (PWD) within South Africa, a study done by Kruger, Puoane, Senekal and van der Merwe (2005) found that a combination of poor environmental conditions with lack of facilities, high crime rates and attitudes towards thin people contribute to low levels of physical activity amongst South Africans. In general there is a lack of research done in PWD with regards to physical activity (PA). The majority of the research focus on disability and employment, housing, basic services and education as illustrated in the South African Census (2011) document. There is therefore not much information on PA opportunities for PWD in South Africa. Bull, Armstrong, Dixon, Ham, Neiman and Pratt (2004) stretch this point in their book, where the authors mention that finding data on PA from countries in the African region was most difficult. This is a concern because of the potential impact that lack of PA can have on a PWD's health and wellness. Rehospitalisations frequently occur and can be reduced through PA. Rehospitalisations do not only affect the individual but ultimately the tax payer and it can become a great economic burden for the general population. PA can help decrease the number of hospitalisations by preventing secondary conditions associated with a SCI, through the many benefits associated with PA. Furthermore, PA not only has physical benefits but it also helps the individual with a SCI complete activities of daily living (ADL) with more ease and improve their quality of life (QOL).

In this chapter a brief outline is given to the challenges that people with disabilities face in order to receive basic human rights such as access to PA and healthcare. This sets the scene for the subsequent chapters that highlight the importance of this study. PWaSCI face many challenges in attaining healthcare and wellness through PA, irrespective of their race, gender and socio-economic background. The Rec Tech RAMP Model (1999) cited in Rimmer, Ainsworth, Young, and La Monte (2008) was used as a guide to design an intervention that targets the many barriers faced by PWaSCI. This model focusses on access, increasing participation and promoting adherence to regular exercise which ultimately leads to improved health and physical function, which is the final outcome desired for the study.

## **1.2. Background to the Study**

### **1.2.1. Disability and Exclusion**

It is estimated that approximately 10% of the world's population have a disability (650 million people). Of the 650 million PWD, 80% live in developing countries (Disabled World, 2015). According to the Convention on the Rights of Persons with Disabilities (Pillay, 2010) some adults and children with disabilities are fully integrated into society, participating and actively contributing to all areas of life. However, the majority of PWD face discrimination, isolation, exclusion and abuse. In the past, society focussed on the disability and what was wrong with the person (Medical model of disability) (Pillay, 2010). More recently the focus has shifted to society and the environment that does not accommodate for individual differences and thus limits or impedes the individual's ability to participate in society (Social model of disability) (Pillay, 2010). According to Mbeki (1997) the social model has two main focuses:

- Shortcomings of society in respect of disability
- Abilities and capabilities of people with disabilities themselves

“This focus requires, that resources, be made available to change “ordinary” amenities and services for a more diverse environment” (Mbeki, 1997:15). The social model of disability has led to many positive changes ranging from accessible buildings and transport to the inclusion of children with disabilities in sport in main stream schools in some countries. In the past the majority of people with disabilities in South Africa have been excluded from mainstream society (Mbeki, 1997). This includes being prevented from accessing social, political and economic rights.

According to Mbeki (1997) and the SAHRC (2002) the exclusion resulted from a range of factors, which included:

- Political and economic inequalities of the apartheid system
- Social attitudes which viewed PWD as being dependent and in need of care
- Discriminatory and weak legislative framework which had sanctioned and reinforced exclusionary barriers

These factors resulted in a cumulative disadvantage in that PWD were poor, unemployed, and lived in social isolation in South Africa (Mbeki, 1997). According to SAHRC (2002:35), South Africa has “one of the most progressive, rights-based constitutions in the world”. Yet PWD are confronted daily with barriers that prevent them from participating in society. According to Mothabeng (2011) PWD have been engaged in a struggle to remove barriers, which has denied them opportunities to integrate into their respective communities and participate as equal members within society. Over the past couple of decades progress has been made, however, PWD still face challenges in terms of equity and access to basic services (Mothabeng, 2011). This is especially true for people living in poor socioeconomic environments with limited resources and lack of infrastructure. The situation is also exacerbated by the fact that there is societal neglect, discriminatory attitudes and barriers in the communities where PWD find themselves (SAHRC, 2002). It is almost 20 years since the democratic dispensation and PWD still face challenges in terms of equity and access to basic services. This is illustrated not only by the large number of people (49.7%) that do not meet the public health recommendations of 150min of health enhancing physical activity per week within the peri-urban community in the Western Cape, South Africa (Joubert *et al.*, 2007). But also by the numerous physical and attitudinal barriers that PWD face in terms of participation in their communities (Chappell and Johannsmeier, 2009).

Disability is a multifaceted phenomenon, however, for the purpose of this research the focus will be on PWaSCI and the barriers they face in attaining the basic human right of health and wellness. The researcher decided to embark on this research as she observed a gap between inpatient rehabilitation and involvement in PA once a patient has been discharged from hospital. The researcher noticed practicing as a Biokineticist in a rehabilitation setting that PWaSCI become hypoactive once they are discharged from hospital. The reason is not necessarily due to a lack of motivation or desire to be inactive but possibly due to social, environmental, personal and program/policy barriers. In developed countries extensive research has been done on reasons why people are inactive and more specifically, the

barriers that are faced by PWaSCI. However, these research findings cannot necessarily be generalised to PWaSCI in South Africa. Although there are some similarities, as a developing country, South Africa's challenges include lack of accessible public transport for PWD (Venter, Bogopane, Rickert, Camba, Venkatesh, Mulikita, Maunder, Savill and Stone, 2002).

### 1.2.2. **Physical Activity Levels in People with a Spinal Cord Injury**

“Physical activity is defined as any bodily movement produced by the contraction of skeletal muscles that result in a substantial increase over resting energy expenditure” (ACSM, 2013:2). According to Caspersen, Powell and Christenson (1985) PA can be categorized into occupational, sports conditioning, household and other activities. The benefits of PA are well known and are further discussed in section 2.4.4. PWaSCI who participate in regular PA have a decreased risk of chronic diseases and can improve their physical fitness, functional independence, social reintegration and psychological well being (Foulon, Lemay, Ainsworth, and Martin Ginis, 2012). Despite the many benefits associated with regular PA, most PWaSCI lead inactive lives. For example, it was reported that approximately 50% of PWaSCI in Canada do not participate in regular PA (Foulon *et al.*, 2012). In a study conducted by Anderson (2004) the researcher found that although not all the participants had access to exercise or did not have access to trained therapists to oversee the exercise, 96.5% considered exercise as an important aspect required for functional recovery.

In South Africa there is a particularly high prevalence of physical inactivity among individuals without a disability, with 49% of adult women and 43% of adult men reporting to be insufficiently active (Joubert *et al.*, 2007). This average is much higher than the global average of 17% and Africa's average of 10%. According to the available statistics a large number of deaths and disability-adjusted life years (DALYs) from associated chronic conditions are attributed to physical inactivity in South Africa (Joubert *et al.*, 2007). The statistics regarding PA levels in PWaSCI in South Africa are hard to find. However, one can only assume that most PWD do not participate in regular PA due to the lack of infrastructure and opportunities that even people without disabilities face in being physically active.

Due to the consequences of a SCI and the various associated health risks, PA is considered even more important in this population (Tasiemski, Kennedy, Gardner and Taylor, 2004a). Especially since PWaSCI are two to five times more likely to die prematurely than people without a SCI (WHO, 2015a). Secondary health problems such as cardiovascular disease, obesity, diabetes (Vissers *et al.*, 2008) and pressure ulcers are some of the major causes of

death in low income countries (WHO, 2015b). According to Kehn and Kroll (2009) some of these conditions can be avoided through regular PA and good health.

There are a number of reasons why PWaSCI do not participate in regular PA. One reason may be due to the secondary conditions mentioned above. According to Martin Ginis *et al.* (2008) another reason may be the lack of evidence-based PA guidelines. This is further supported by Spinal Cord Injury Research Evidence (SCIRE, 2010) who stated that effective interventions that promote PA should be researched, since a large segment of this population is inactive. Other barriers include lack of facilities, equipment cost, fear of injury and lack of personal assistance (Kehn and Kroll, 2009). Vissers *et al.* (2008) found that shortly after discharge from hospital, factors such as self-care, accessibility of buildings, lack of transport and societal attitudes had the highest impact on everyday PA levels. The multitude of barriers should, however, not detract researchers' attention and efforts from the core issue, namely that PA is essential in reducing the risk of developing secondary conditions and that solutions must be found to address and overcome these barriers.

According to Rimmer (2012) there is a strong justification for a new paradigm which closes the gap between inpatient rehabilitation and community based PA. During rehabilitation there is a short term gain in health and function. This is only enough to get the patient above the minimum level of the functional threshold, which allows for performing ADL and stabilizing health. After a few weeks of gradual improvement, the individual plateaus for a short period and then reaches an inflection point where the patient's health can either improve or decline. According to Rimmer (2012) the more likely route is a decline in health and ultimately succumbs to an increase in the risk of multiple chronic conditions associated with a sedentary lifestyle. This can occur approximately 12 weeks after rehabilitation and in some cases even after eight weeks (Rimmer, 2012). However, if a PA regimen is introduced at the inflection point, the gains made during rehabilitation are sustained and depending on the amount of PA or exercise, small to large improvements in health and function can be observed. People with newly acquired disabilities thus need to establish a routine that includes PA. For instance, Levins, Redenbach and Dyck (2004) found that persons with paraplegia who were involved in wheelchair sports had less hospitalisations and major medical complications. Yet PWaSCI are rarely the target for health promotion efforts, which could lead to increased job acquisition, retention and reduced medical costs (societal burden) within this population. Rimmer (2006) also stated that PWD who have higher levels of PA after the rehabilitation process, have higher levels of community reintegration compared to their "peers" who have lower or inactive lifestyles after rehabilitation. To

emphasize this point the Centre of Disease Control (CDC) (2015) stated that regular PA is one of the most important activities you can do for your health.

### 1.2.3. **Physical Activity Opportunities for Persons with a Spinal Cord Injury**

In South Africa very few PWD have opportunities to participate in PA or sport, especially within the rural areas. In South Africa there are 23 rehabilitation facilities, which include 17 spinal rehabilitation units. Most of these facilities are centred in urban and socio-economically advantaged areas, whereas most persons within South Africa live in rural and socio-economically disadvantaged areas (Booyesen, 2003). These 17 spinal units are equally distributed between the public and private sector, with one unit in the Western Cape being both public and private. According to the Department of Health (2003) 80% of the South African population is dependent on the government for healthcare and only 20% of the population utilises private healthcare. Thus the majority of the population within South Africa have access to only eight facilities for rehabilitation. Therefore the majority of the South African population are being neglected in terms of access to adequate healthcare, to which they are entitled. Collectively this leads to long waiting lists for in-patient rehabilitation and early discharge from rehabilitation (Mothabeng, 2011). The ultimate goal of SCI rehabilitation is community reintegration, which includes maximal possible functional independence and return to a pre-injury lifestyle (DeVivo and Richards, 1992). After discharge PWaSCI face the fact that there are less training opportunities than there were in the hospital as well as more ADL to complete by the individual him-/herself (Haisma *et al.*, 2006). The lack of PA opportunities also contributes to a sedentary lifestyle within this population (Jacobs and Nash, 2004) which may ultimately lead to rehospitalisation due to secondary conditions.

Due to the lack of research that has been conducted in PWaSCI and PA, it appears that very little is known about the extent of PA in PWaSCI, as well as the barriers and facilitators to PA within South Africa. There is also a lack of PA guidelines and interventions which may successfully help in managing and preventing secondary conditions, improve physical abilities, and fostering community reintegration and community based health and wellness. It is therefore imperative that an intervention program be developed that is community based, accessible and that will allow PWaSCI achieve health and wellness through PA. Sustainability of a PA program is essential in order to achieve health and wellness and to avoid or reduce the occurrence of secondary complications associated with a SCI. To the researcher's knowledge there are very few facilities that are accessible and cater for PWaSCI to be physically active.



### **1.3. Problem Statement**

South Africa has a unique history in terms of human rights. In the apartheid years certain individuals and cultures were deprived of equity and basic human needs. Furthermore, during the apartheid struggle and pre-democratic era political violence was the cause of many disabilities (Mothabeng, 2011). Although apartheid has ended, interpersonal violence still exists and is one of the major causes of SCI in South Africa. According to Mothabeng (2011) this violence is due to urbanisation and the ongoing socio-economic discrepancies that still exist.

Once patients are medically stable and admitted to inpatient rehabilitation, they are surrounded by health care professionals such as physiotherapists, occupational therapists and psychologists to help them cope with their injury. However, upon discharge these services are no longer readily available and the person faces his or her community alone, whether they are ready or not. Health and wellness is a basic human right and within South Africa due to the lack of PA opportunities for PWD, and more specifically PWaSCI, this basic human right is often not achieved. Mothabeng (2011) observed that 48% of PWaSCI are re-admitted to hospital for a number of health complications soon after discharge. This suggests that PWaSCI are not coping with their injury and does not achieve healthy living within their communities. They are struggling with secondary conditions that at times result in death soon after discharge (Mothabeng, 2011). Health care professionals within the hospitals are responsible for making sure PWaSCI are able to prevent, identify and manage secondary conditions should they occur. However, without proper training, PWaSCI are unable to take responsibility for their own health and wellness (Mothabeng, 2011) and are therefore dependent on auxiliary services, which are seldom available.

There are potentially many reasons why PWaSCI do not achieve adequate levels of health and wellness. For the purpose of this research the focus is on the different barriers that PWaSCI face in being physically active. Given the importance of PA it is imperative that the reasons for physical inactivity be identified in order to implement effective strategies that will promote PA behaviour and ultimately health and wellness within this population.

#### **1.3.1. The role of a Biokineticist**

Biokinetics is defined as “the science of movement and the application of exercise in rehabilitative treatment or performance” (Biokinetics, 2015). The profession uses PA as medicine. Therefore support can be provided with functional exercises, strength and

endurance, altogether fostering independence and an active lifestyle within the individuals' community.

In PWaSCI deconditioning is inevitable and leads to other medical complications such as diabetes mellitus, heart disease, arterogenic lipid profiles and hypertension as a result of a sedentary lifestyle. These problems collectively affect ADL, QOL and contribute to accelerated aging (Jacobs and Nash, 2004; van den Berg-Emons *et al.*, 2008). Although exercise and an active and healthy lifestyle seem like a pretty straight forward solution, it is not the case for PWaSCI. However, Biokineticists can help rehabilitation professionals to bridge the gap that exists between inpatient rehabilitation and successful community reintegration, by providing additional support through PA programs and the training of volunteers to assist and run community based PA programs under their supervision.

### **1.3.2. The Significance of the Research to the South African Department of Health**

Research that has been conducted in PWaSCI in South Africa includes:

- A survey on the needs of persons living with a SCI (Cock, 1989)
- An evaluation of the health promotion needs of youth living with a SCI in the Western Cape (Njoki *et al.*, 2004)
- An exploration of the experiences of people living with SCI in the Eastern Cape (Magenuka, 2006)
- The impact of SCI on South African youth (Njoki *et al.*, 2007)
- A survey of the problems encountered by black tetraplegic patients once discharged from hospital (Monageng, 2007)
- An evaluation of functioning of primary school children living with paraplegia in the Western Cape (Vosloo, 2009)
- Community participation for persons living with a SCI in the Tshwane Metropolitan area (Mothabeng, 2011)

Most of these studies included an aspect of community integration/participation, however, in order to function optimally within a community a certain degree of health and wellness is required and is often missing in research.

Currently, to the researcher's knowledge, very little is known with regards to community based PA programs within South Africa that addresses the barriers faced by PWaSCI. This

includes information on whether such programs are possible in terms of being implemented, cost effective, the recruitment and training of volunteers to assist in running the programs and whether it is sustainable. This study addresses these issues concerning access, program costs, lack of trained volunteers, and reducing the risk of secondary health conditions through PA. Such information could be beneficial to the government in order to create policies and provide financial assistance in order to implement such programs nationally in order to reduce the current problems that exist within this population.

#### **1.4. Scope of the Study**

Although there are two main parts to the research, the delimitations of the study remain the same. All the participants in this study resided in the Western Cape and therefore the results cannot be generalized to a larger population.

#### **1.5. Assumptions**

The study was divided into two main parts namely, Phase I the research questionnaire and Phase II the intervention. There are therefore different assumptions to each section.

##### **1.5.1. Phase I: Pilot Study and Research Questionnaire**

It was assumed that the participants answered the research questionnaire as accurately and honestly as possible. It was also assumed that the small sample size will be sufficient to evaluate the questions in the questionnaire and that the research questionnaire will address the constraints faced by PWaSCI.

##### **1.5.2. Phase II: Intervention**

It was assumed that the participants would fully cooperate in the study and answer questions honestly and attend most if not all sessions. It was also assumed that the small sample size (n=57) will be sufficient to evaluate the participants' program adherence and improvements in physical abilities.

#### **1.6. Purpose of the Study**

This study endeavoured to bridge the gap between inpatient rehabilitation and community based health and wellness through PA. Bridging the gap means identifying the constraints faced by PWaSCI that prevents them from being PA, attaining health and wellness through PA and finding ways to overcome the barriers, where possible.

## 1.7. Aim and Objectives

### Phase I

**Primary Aim 1:** To identify the barriers that prevents PWaSCI from being physically active via the research questionnaire.

**Objective 1:** Identify Personal/Individual constraints

**Objective 2:** Identify Social constraints

**Objective 3:** Identify Environmental constraints

**Objective 4:** Identify Program/Policy constraints

### Phase II

**Primary Aim 2:** To develop a physical activity program that targets these barriers and constraints identified by the participants in order to facilitate a physically active lifestyle that helps to improve community reintegration.

**Objective 1:** To compare the impact of a general exercise program in a formal (WCRC group) and community based (Strand and Macassar group) setting on the physical abilities (cardiovascular endurance, strength, functional ability and community reintegration (RNLI)) of the participants at pre, two and four months post-intervention.

**Primary Aim 3:** To determine the impact of a physical activity program on physical activity adherence in SCI population.

**Objective 1:** To compare the perceived barriers pre and post-intervention for the different training environments.

## 1.8. Research Questions

Based on the above information, the researcher sought to answer the following questions:

1. What are the barriers to physical activity faced by PWaSCI?
2. Can a community based physical activity program designed to reduce the previously identified barriers help improve physical abilities of PWaSCI? Furthermore, can a physical activity program operate similarly in a community setting and a formal exercise setting?
3. Did the perceived barriers to physical activity change after commencement of the rehabilitation program? If so, were new barriers identified?

## 1.9. Key Terminology

Below key terminology used in this thesis are defined.

### 1.9.1. **Activities of Daily Living (ADL)**

ADL refer to the personal activities of daily living and require basic skills and focus to take care of one's own body. ADL include self care tasks such as bathing, bowel and bladder management, dressing and undressing, eating, feeding, functional mobility such as bed mobility and transfers, sexual activity, toilet hygiene and care of personal devices (Foti and Koketsu, 2013).

### 1.9.2. **Barrier**

A constraint or barrier is something that limits or restricts someone's actions or behavior (Merriam-Webster Dictionary, 2015).

### 1.9.3. **Community Based Setting**

For the purpose of this research a community based setting is defined as an environment identified within a specific community that is accessible to PWaSCI, volunteer driven, within close proximity to the individual's place of residence and is equipped with basic exercise equipment that allows for PA participation.

### 1.9.4. **Community Reintegration**

Community reintegration includes relationships with others, independence in ADL and spending time meaningfully (De Wolf, Lane-brown, Tate, Middleton and Cameron, 2010).

A definition associated with the SCI population includes "resuming age/gender and culturally appropriate roles/statuses/activities including independence/interdependence in decision making and productive behaviours performed as part of multi-varied relationships with family, friends and others in natural community settings" (De Wolf *et al.*, 2010:1185).

### 1.9.5. **Disability**

Disability is an evolving concept and results from interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (Pillay, 2010).

The International Classification of Functioning (ICF), Disability and Health define disability as an umbrella term for impairments, activity limitations and participation restrictions. Disability is the interaction between individuals with a health condition (e.g. cerebral palsy, Down

syndrome and depression) and personal and environmental factors (e.g. negative attitudes, inaccessible transportation and public buildings, and limited social supports). (WHO, 2016).

#### 1.9.6. **Exercise**

“Exercise is a type of physical activity consisting of planned, structured, and repetitive bodily movement done to improve or maintain one or more components of physical fitness” (ACSM, 2013:2).

#### 1.9.7. **Facilitator**

A facilitator is one that helps to bring about an outcome (as learning, productivity, or communication) by providing indirect or unobtrusive assistance, guidance, or supervision (Merriam-Webster Dictionary, 2015).

#### 1.9.8. **Formal Exercise Setting**

For the purpose of this study a formal exercise setting is defined as an environment that is accessible to PWaSCI, professionally equipped with exercise equipment and manned by health-care professionals.

#### 1.9.9. **Health and Wellness**

Health is a state of complete physical, mental and social well being and not merely the absence of disease or infirmity (WHO, 2015c).

Wellness is an active process of becoming aware of and making choices toward a more successful existence (National Wellness Institute, (nd)).

#### 1.9.1. **Physical Activity**

“Physical activity is defined as any bodily movement produced by skeletal muscles that require energy expenditure” (ACSM, 2013:2).

#### 1.9.1. **Physical Fitness**

“Physical fitness is a set of attributes or characteristics that people have or achieve that relates to the ability to perform physical activity” (ACSM, 2013:2).

#### 1.9.2. **Rehabilitation**

Rehabilitation is defined as "a set of measures that assist individuals, who experience or are likely to experience disability, to achieve and maintain optimum functioning in interaction with their environments" and is instrumental in enabling people with limitations in functioning to

remain in or return to their home or community, live independently, and participate in education, the labour market and civic life (WHO, 2015d).

### **1.9.2.1. Definition of Rehabilitation for People with a Disability (PWD)**

Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological, social and functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination (WHO, 2015d).

### **1.9.3. Spinal Cord Injury (SCI)**

SCI involves damage to any part of the spinal cord or nerves at the end of the spinal canal. It often causes permanent changes in strength, sensation and other body functions below the site of the injury (Mayo Clinic, 2015a).

## **1.10. Outline of Chapters**

Chapter one introduces the research project by highlighting the support and significance of the study, and the research questions that guided the process. The subsequent chapter, chapter two, examines the body of knowledge that is available in SCI research in terms of what a SCI is and the cascade of events that take place following such an acquired injury. It looks at hospitalisation and the phases of rehabilitation, the effects of physical activity (PA) and health and wellness within PWaSCI and the reasons why PWaSCI become either physically active or inactive.

Chapter three (methodology) focuses on how the researcher conducted and executed the study. This includes the pilot study, Phase I (Research Questionnaire) and Phase II (Intervention) of the main study. The chapter looks at research setting, study design, study population, methods of data collection and statistical analysis.

In chapter four the results of Phase I is presented and discussed, which is followed by the presentation and discussion of the results of Phase II in Chapter five. In chapter six final conclusions are made, the strength and limitations of the study are discussed and reference is made to future research recommendations and practical implications of the study.

## CHAPTER 2

### THE GREAT DIVIDE

#### 2.1. Chapter Overview

This chapter will explore the current situation regarding a spinal cord injury (SCI), its impact on quality of life (QOL) and the possible impact of physical activity (PA) on QOL. The goal of reintegration is also discussed, highlighting the barriers to reintegration and possible intervention strategies to facilitate reintegration in research. Lastly, the chapter looks at different theories that guided attempts to improve PA behaviour after the rehabilitation process.

##### 2.1.1. A Brief History

In 1944 during the second World War Sir Ludwig Guttmann a Jewish neurosurgeon opened a National Spinal Injuries Centre (NSIC) at the Stoke Mandeville hospital in England. He used sport as a form of rehabilitation and as a means to improve function and independence in soldiers with a disability (Stephens, Neil and Smith, 2012). Guttmann realised the benefits of sports and thus he challenged the attitudes towards the physical abilities of persons with disabilities (PWD) (Thomas and Smith, 2009).

“Since this introduction, participation in regular sporting activity is thought to offer physical and psychological benefits for disabled individuals.” (Stephens, Neil and Smith., 2012:2061)

In 1948 Guttmann and the hospital staff hosted the first Stoke Mandeville Games, which was held on the same day as the opening of the London Olympic Games (Thomas and Smith, 2009). He compared the Stoke Mandeville Games to the Olympics and said that it will eventually be the “paraplegic’s” equivalent to the Olympic Games. In 1952 the first International Stoke Mandeville Games was held and a total of 130 wheelchair athletes with spinal cord injuries participated. From this movement many other sport organisations started and the first Paralympics was held in Rome in 1960 (Thomas and Smith, 2009). Since 1944 sport has been used as a tool in the rehabilitation process to help PWD overcome many barriers whether physical, psychological or social (Thomas and Smith, 2009). Sport has also been used to give PWD a sense of purpose and show off their abilities through competitive sport events such as the Paralympics. Lastly sport has also been used for health and



recreational purposes to foster social and personal development. In this study PA will be used to help PWaSCI attain health and wellness.

## **2.2. The Spinal Cord and Spinal Cord Injury**

The spinal cord (SC) forms part of the central nervous system (CNS) and is the vital communication link between the brain and the body that coordinates and initiates bodily functions (Prentice, 2009). The SC extends from the foramen magnum (bottom of the skull) to the first or second lumbar vertebra (filum terminale) and is composed of five main segments namely the cervical (7 vertebrae), thoracic (12 vertebrae), lumbar (5 vertebrae), sacral (5 vertebrae) and coccygeal region(4 vertebrae). It is hosted within the vertebral canal. The vertebral canal consists of 33 vertebra, of which twenty four of these vertebra (cervical and thoracic) are moveable and nine are immovable (lumbar and sacral) (Prentice, 2009). The spinal cord is a cylindrical structure of nervous tissue, with peripheral nerves that extend from the spinal cord at each vertebra. The lumbar roots and sacral nerves also known as the cauda equine form an extension of the cord. The SC consists of upper and lower motor neurons that function as a bidirectional channel between the brain and its motor, sensory and autonomic targets (Jacobs and Nash, 2004). It also functions as a reflex integration centre between the body's sensors and their respective motor and autonomic effectors (Jacobs and Nash, 2004). The SC conveys information via different tracts namely the afferent (ascending) and efferent (descending) tracts. These tracts function as a communication system between the body and the brain. The afferent tracts receive information from the body through sensory neurons (internal organs and external stimuli) and carries the information to the brain (brain interprets information and generates appropriate response), while the efferent tract send information from the brain to the organs, glands and muscles (motor function) through motor neurons. The messages transmitted by the SC include pain, movement, temperature, touch and vibration regarding skin, joints, muscles and the internal organs (Brain and Spinal Cord, 2015).

A SCI refers to the neurological damage caused by trauma to the SC. Common areas of injury include the cervical and the thoracolumbar area due to increased mobility, with C5-6 being the most common area (Disability in Action, 2014). A SCI results in segmental neuromuscular, autonomic and physiological impairment of the legs, arms, trunk or a combination of the above (Figoni, 2009). The level of the SCI, and whether the injury is complete or incomplete, determines the residual functional abilities of the individual. The functional outcome is determined through the American Spinal Injury Association (ASIA) classification system. The classification is based on a standard sensory and motor assessment. Injuries are classified as either ASIA A (complete injury) or ASIA B, C, D or E

(incomplete injury). A complete transection of the spinal cord is rare and is mainly caused by penetrating injuries such as gunshot and knife wounds (Livecchi, 2011). A complete injury results in the loss of sensation and voluntary movement of the body parts which are innervated by the segments below the lesion. This type of injury is irreversible. On the other hand, a patient with an incomplete injury may experience considerable neurological recovery and improvement. This type of recovery, however, may take several years (Livecchi, 2011). A SCI is classified according to the level of injury and into two main categories namely, paraplegia and quadriplegia/tetraplegia. Paraplegia is caused by injury to the spine below the cervical region (thoracic, lumbar and sacral regions of the spine). In a person with paraplegia the upper extremity function is normal, with loss of function in the trunk and lower limbs. Tetraplegia is caused when the cervical region of the spine (C1-C7) is damaged and leads to all four limbs being affected. The level of injury determines the functional ability of the individual (Table 1 and 2). Table 1 was adapted from Livecchi (2011:579).

**Table 1: Functional outcomes for cervical lesions**

<b>Function</b>	<b>C3-C4</b>	<b>C5</b>	<b>C6</b>	<b>C7</b>	<b>C8-T1</b>
<b>Muscle</b>		Bicep Elbow flexion	Extensors Wrist extension	Triceps Elbow extension	Flexors Finger flexion
<b>Feeding</b>	With adapted equipment	Independent with equipment after set up	Independent with equipment	Independent	Independent
<b>Grooming</b>	Dependent	Independent with equipment after set up	Independent with equipment	Independent with equipment	Independent
<b>Upper extremity dressing</b>	Dependent	Requires assistance	Independent	Independent	Independent
<b>Lower extremity dressing</b>	Dependent	Dependent	Requires assistance	May be independent with equipment	Independent

<b>Bed mobility</b>	Dependent	Requires assistance	Independent with equipment	Independent	Independent
<b>Weight shifts</b>	Independent with power chair, dependent in manual chair	Requires assistance	Independent	Independent	Independent
<b>Transfers</b>	Dependent	Requires assistance	Possibly independent with transfer board	Independent with or without board except floor transfer	Independent
<b>Wheelchair propulsion</b>	Independent with power chair, dependent in manual chair	Independent with power chair; short distances in manual chair with lugs or plastic rims on level surfaces	Independent in manual chair with plastic rims on level surfaces	Independent except curbs	Independent
<b>Driving</b>	Unable	Unable	Specially adapted van	Car with hand controls or adapted van	Car with hand controls or adapted van
<b>Bowel and bladder</b>	Dependent	Dependent	Independent with bowel; needs assists with bladder	Independent	Independent

**Table 2: Functional outcomes for thoracic and lumbar spine (Adapted from Kirshblum *et al.*, 2007:63)**

Measure	T2-T9	T10-L2	L3-S5
<b>ADL's (grooming, bathing, feeding, dress)</b>	Independent	Independent	Independent
<b>Bladder, bowel</b>	Independent	Independent	Independent
<b>Transfers</b>	Independent	Independent	Independent
<b>Ambulation</b>	Standing frame, tilt table/standing wheelchair, exercise only	Household ambulation with orthoses; can trail ambulation outdoors	Community ambulation is possible
<b>Braces</b>	Bilateral KAFOs with forearm crutches / walker	KAFOs with forearm crutches	Possibly KAFOs / AFOs with canes / crutches

### 2.2.1. Aetiology and Incidence Rate

The majority of research done within PWaSCI is found within developed countries and therefore it is difficult to determine what the causes of SCI are globally. The most common aetiology in the USA include motor vehicle accident (43.5%), falls (22%), penetrating injuries such as a gunshot wound (17.2%) and sports injuries (8%). Fall incidents are most common in individuals 60 years and older and the most common sports injury is diving (Livecchi, 2011). Within South Africa the most common causes of traumatic SCI include motor vehicle accidents and violent crimes such as gunshot wounds and stabs (Moodley and Pillay, 2013). Other causes include fall from heights, diving accidents, especially in shallow water and sports injuries. Non traumatic causes include tumours, infections or disk degeneration of the spine (Mayo Clinic, 2015c). Although the numbers are not known in South Africa, there is a similarity in the aetiology of these injuries in comparison with the USA.

The worldwide prevalence and incidence of SCI is difficult to determine due to the lack of efficient systems that allow for the recording of these injuries. Most recordings are found in developed countries such as the USA, where efficient systems are in place such as the National Model Spinal Cord Injury Systems Database. Table 3 illustrates that South Africa (S.A.) has a lower SCI incidence rate per million inhabitants than the world, but falls in the same category as the USA, which is a much larger country.

**Table 3: Spinal cord injury incidence rates**

Country	Incidence/million inhabitants	Reference
<b>Worldwide</b>	223-755	Wyndaele and Wyndaele (2006)
<b>USA</b>	25-55	Sadowsky <i>et al.</i> (2002)
<b>USA</b>	40	Livecchi (2011)
<b>Australia</b>	<15	O'Connor (2005)
<b>South Africa</b>	12.5-38.5	QASA and Dept. Health SA (2003)

Within South Africa there is a lack of reliable information and statistics regarding incidence rates. This is mainly due to the fact that there are “different definitions for disability, various and inappropriate research methodologies and techniques, a failure to collect data from remote and underdeveloped areas and lastly a lack of prioritization of the needs of people with disabilities in social and economic planning” (SAHRC, 2002:12). According to the Quadriplegic Association South Africa (QASA) approximately 500 South Africans sustain a SCI as a result of trauma each year (Njoki, Frantz and Mpofu, 2007). According to Sereilis (2009), as cited in Conran (2012), there are over 50 000 people living with a SCI in South Africa.

According to Sadowsky *et al.* (2002) SCI predominantly affects persons between the ages of 16-30 years, with the dominant sex being male (O'Connor, 2005). This is confirmed in a study conducted by O'Connor (2005) who compared the incidence rates between the USA and Australia and found that the highest incidence rate was between the ages of 15-24 years. With 93% of participants indicating that the injury was not intentional, three percent of persons with SCI admitted to intentional self harm, two percent due to assault and the rest due to legal intervention, medical care and events of undetermined intent. In a study done by Wyndaele and Wyndaele (2006) the researchers found that men seem to be more at risk for a SCI than women with the mean age of sustaining the injury being 33 years. The ratio between men and women sustaining such an injury is 4:1 (Wyndaele and Wyndaele, 2006; Livecchi, 2011). Within South Africa most of these injuries occur between 15-29 years of age (Njoki, Frantz and Mpofu, 2007).

### 2.2.2. Stages of Rehabilitation and Secondary Complications after a SCI

A SCI results in many different regions of the person being impaired (Keleher, Dixon, Holliman, and Vodde, 2008). Hence treatment of such a permanent injury ranges from rehabilitation of several bodily systems to actual and potential mental health issues.

“Rehabilitation begins in the intensive care setting and includes addressing the SCI-specific need to help each person meet his/her potential in terms of medical, physical, social, emotional, recreational, vocational and functional recovery.” (Kirshblum *et al.*, 2007:62)

According to Kirshblum *et al.* (2007; 2011) if early medical complications can be prevented the inpatient rehabilitation process can be initiated, which also leads to the total cost of care being lessened. It is important that early SCI specific rehabilitation be initiated as soon as possible, not only to reduce health care costs but also for the patient as it ultimately influences functional capability and increase the patient’s length of rehabilitation stay (Kirshblum *et al.*, 2011).

According to Mothabeng (2011) spinal rehabilitation programs aim to enhance the residual functional abilities of the person in order to promote participation in everyday life and improve QOL. Kirshblum *et al.* (2007; 2011) also stated that during early recovery one of the primary goals is to convey that life with a SCI can be fulfilling. According to the South African Society of Physiotherapy (SASP) (2004) there are three main stages in the rehabilitation process (Table 4) compared to the six phases described by Landrum *et al.* (1995).

**Table 4: Stages of rehabilitation (Fekete and Rauch, 2012)**

<b>Stage of Rehabilitation (SASP, 2004)</b>	<b>Level of Rehabilitation (Landrum <i>et al.</i>, 1995)</b>	<b>Descriptive Title (Landrum <i>et al.</i>, 1995)</b>
<b>Early (Hospitalisation)</b>	Level 0	Physiological instability
	Level 1	Physiological stability
<b>Mid (Inpatient rehab)</b>	Level 2	Physiological maintenance
	Level 3	Home/Residential integration
<b>Late</b>	Level 4	Community reintegration
	Level 5	Productive activity

Moving from one stage to the next is not always as linear as discussed above and entering a stage may occur at any time and is dependent on the individual and other complications (Mothabeng, 2011).

### 2.2.2.1. Early Rehabilitation (Hospitalisation)

After a SCI a cascade of events occurs within the human body. A progressive state of degeneration is initiated and includes structural, biochemical and physiological changes that occur over weeks to months post injury (Houle and Côté, 2013). Secondary changes are inevitable after trauma and include inflammation, excitotoxicity, apoptosis of neurons and glia, axon retraction, glial scarring, demyelination and exposure of myelin associated inhibitory molecules, changes in electrophysiological properties of neurons and aberrant sprouting/plasticity of spared nerve fibres (Houle and Coté, 2013). The primary approach to initial hospitalisation is firstly to ensure medical and surgical stabilization after which the secondary goal is to prevent secondary injuries/complications through the removal of damaging bones, discs and ligament fragments, as well decompression (Sadowsky *et al.*, 2002). After stabilization, acute and long term rehabilitation can commence (Sadowsky *et al.*, 2002).

Since a considerable amount of neurological recovery takes place within the first months after sustaining a SCI, it is imperative to determine the appropriate time for the onset of rehabilitation (Scivoletto, Morganti and Molinari, 2005). Backus *et al.* (2013) supported this view by highlighting the critical role of the timing of service delivery post SCI. Inpatient rehabilitation is considered a primary treatment method for persons with a traumatic SCI and is associated with functional gains and should therefore occur as soon as possible after the injury (Hammond *et al.*, 2013). According to Hammond *et al.* (2013), in addition to education and interventions provided by social workers, nurses and physicians, the most important treatments during acute rehabilitation include occupational therapy (OT), physical therapy (PT), psychology and therapeutic recreation (RT). Sumida *et al.* (2001) found that persons who received early versus late rehabilitation (30 days post injury) had better motor outcomes, fewer secondary complications and fewer rehospitalisations. Scivoletto, Morganti and Molinari (2005) found that early rehabilitation was associated with greater improvement in activities of daily living (ADL's) when compared to later rehabilitation. According to Scivoletto, Morganti and Molinari (2005) the best functional recovery occurs in the early weeks of treatment after the person sustained a SCI and that the effectiveness of rehabilitation decreases after the first weeks of treatment. Other studies also found that early SCI rehabilitation to be beneficial (Sumida *et al.*, 2001; Whiteneck *et al.*, 2009) and that initial functional status is associated with functional improvements and length of stay (Scivoletto, Morganti and Molinari, 2005; Whiteneck *et al.*, 2009). Researchers therefore agree that the earlier rehabilitation is initiated, the better the outcome for each individual with a SCI. However, according to Backus *et al.* (2013) admittance to rehabilitation is related to

health and severity of the injury and the less severe or the more healthy the individual the earlier they are admitted to rehabilitation.

#### **2.2.2.2. Mid- Rehabilitation (Inpatient Rehabilitation)**

According to Keleher, Dixon, Holliman, and Vodde (2008) rehabilitation is the most important source of treatment for a person who acquired a permanent injury such as a SCI. Essentially rehabilitation is the process by which the injured individual is taught to live with the disability in their environment (Keleher, Dixon, Holliman, and Vodde, 2008). Because of the multiple systems that are affected by such an injury, an interdisciplinary team with different expertise is involved. Members of this task team include physicians, nurses, dieticians, social workers, psychologists, pharmacists, physiotherapists, occupational therapists and speech therapists. During this part of the rehabilitation process the person with a newly acquired SCI begins to adjust to the physical limitations imposed on them by the injury. Hence exercising and maintaining range of motion (ROM) in the joints and muscles is important not only for physical rehabilitation but also for general health management (Keleher, Dixon, Holliman, and Vodde, 2008). The patient now also has to learn how to mobilise his/her body by using different devices depending on the lesion level. Some may use prostheses and others wheelchairs. Short and long term functional goals can also now be set and therapy prescription is established (Kirshblum *et al.*, 2007).

The goal of this phase in the rehabilitation process is to promote as much independence as possible, whilst at the same time reducing the effects of pain caused by the injury, as well as fatigue (Keleher, Dixon, Holliman, and Vodde, 2008). According to Angel, Kirkevold and Pedersen (2011) the process of rehabilitation is embodied by conflicting and different emotions, which include despair, hope, depression, optimism and disappointment. Although progress is evident during the rehabilitation process, most patients feel like giving up. Thus the pace and effectiveness of a rehabilitation program is largely dependent on the patient's efforts (Angel, Kirkevold and Pedersen, 2011). During inpatient rehabilitation the individual is also highly dependent on support from rehabilitation professionals, due to the loss in muscle strength and psychological distress. Hence the interdisciplinary team is required for this phase of the process in order to ensure that the patient is properly prepared for the final phase of the rehabilitation process.

#### **2.2.2.3. Late - Rehabilitation (Community Reintegration)**

The late stage of rehabilitation focuses on the achievement of maximal level of functioning and include; self management, social competencies, community mobility, full integration into productive activities (set according to the person's functional capacity, interests and stage of



life) and participation in sport and recreation within their respective communities (Mothabeng, 2011). It is during this final stage that the readiness of the individual to live and function within the community is tested.

Ideally rehabilitation should now commence within the community and provision for this is made through the South African National Department of Health through community service (Compulsory Community Service (CCS)). This is the ideal, however, due to the lack of post discharge follow ups and re-assessment, the effectiveness of this phase of the rehabilitation process is not evaluated. According to Carpenter (1994) the lack of follow up prevents the intervention team to evaluate the successfulness of their interventions beyond that of the hospital and/ or rehabilitation centre. Apart from these challenges, South Africa faces an even greater challenge in the fact that there are very few facilities catering for PWD in general. This leads to the majority of the South African population being neglected in terms of access to adequate healthcare to which they are entitled (Mothabeng, 2011). As mentioned above this leads to early discharge and most of the time equates to the person not being ready to face their community and lists of duties that have to be done outside of the rehabilitation facility in order to “survive”. Although patients are not ready to leave the hospital they do not have much say in the matter as the hospitals are overcrowded and the staff overworked.

In a study conducted by Mothabeng (2011) in the Tshwane metropolitan area, South Africa, all of the participants reported that they were generally satisfied with their rehabilitation. However, according to Mothabeng (2011) this overwhelming appreciation of rehabilitation must be interpreted with caution. Mothabeng, Malinga, Van der Merwe, Qhomane, and Motjotji (2007) mentions that patients are usually grateful for the help they receive regardless of the quality thereof. Although all the participants demonstrated satisfaction with their rehabilitation some indicated that they were dissatisfied by the way they were treated by rehabilitation professionals. Most of the dissatisfaction, however, was directed at nursing staff and physiotherapists pushing the patients too hard. These findings were also supported by Cott (2004) who conducted the study in Ontario, Canada and in a review by Whalley Hammell (2007). The authors stated that the experience a person has during institutionalised rehabilitation has an effect on their outcome following discharge and that the experience is shaped by the attitude of the rehabilitation staff. According to Levins, Redenbach and Dyck (2004) rehabilitation programs focus on instructing individuals in mobility techniques and how to perform ADL, but does not take long term health needs into consideration. Due to a decrease in the length of rehabilitation, reduced health care funding and changing

intervention approaches, there is little time to address the issues of physical activity (PA) (Levins, Redenbach and Dyck, 2004).

The decreased length of stay during inpatient rehabilitation has also led to the development of outpatient programs in order to “bridge the gap” (Backus *et al.*, 2013). Following acute rehabilitation, patients are transferred into their community, where they are expected to start a new life. They are expected to reintegrate into their community, which includes maximal possible functional independence and return to pre-injury lifestyle (DeVivo and Richards, 1992). However, after discharge PWaSCI face the fact that there are less training and rehabilitation opportunities than there were in the hospital as well as more ADL to complete (Haisma *et al.*, 2006). Specialists in SCI within South Africa (e.g. Biokineticists) are able to design physical fitness programs in order to prevent functional loss, however, according to Sadowsky *et al.* (2002) most patients are treated by non-specialists.

It is evident that early discharge is a problem and leads to patients not being ready for their communities and the challenges that lie ahead. This leads to improper management of secondary conditions and ultimately rehospitalisation. The lack of information regarding PA during inpatient rehabilitation is also frightening as patients are not aware that PA is necessary, and can help prevent secondary conditions, and improve their functional ability and ultimately QOL.

### **2.3. Secondary Complications**

According to Adriaansen *et al.* (2013:1104) a secondary health condition (SHC) is defined as:

“...physical or psychological health conditions that are influenced directly or indirectly by the presence of a disability or underlying physical impairment”.

Secondary complications after a SCI is extremely common (Chiodo *et al.*, 2007; Rimmer and Henley, 2013). According to the Model Spinal Cord Injury Systems Data the incidence of secondary conditions changes according to the number of years that the person has had the SCI (Chiodo *et al.*, 2007). SHC's include bladder and bowel disorders, pressure ulcers, spasticity, upper extremity pain, obesity and cardiovascular and respiratory conditions (Table 5) (Adriaansen *et al.*, 2013).

**Table 5: Secondary Conditions: Pressure Ulcers, Urinary and Respiratory conditions**

<b>Condition</b>	<b>Prevalence</b>	<b>Reference</b>
<b>Pressure ulcers and Pneumonia</b>	Most common secondary conditions. Pneumonia is more common in tetraplegics and elderly.	Chiodo <i>et al.</i> (2007) DeJong <i>et al.</i> (2013)
<b>Pressure ulcers</b>	Pressure ulcers were found in 20-31% of PWaSCI.	Hammell (2010)
<b>Pressure ulcers and urinary complications</b>	Mostly seen in patients with a complete injury. Amongst the most common conditions.	DeJong <i>et al.</i> (2013) Adriaansen <i>et al.</i> (2013)
<b>Respiratory diseases</b>	Major cause of deaths in SCI 72.3% due to Pneumonia.	Chiodo <i>et al.</i> (2007)
<b>Respiratory and heart disease</b>	Leading causes of death after the first year post injury.	Krause and Saunders (2011)

According to Adriaansen *et al.* (2013) several studies have evaluated the relationship between aging and SHC. In a longitudinal cohort study by Hitzig, Campbell, McGillivray, Boschen, and Craven (2010) it was found that the reporting of spasticity, kidney disorders, high blood pressure (HBP) and chronic pain increased over time and this was irrespective of age and time since injury. Other results showed that with time and increasing age, cardiac and respiratory problems increased, while the risk of bladder infections decreased with age. It was also found that with increasing time since injury the chances of developing pressure ulcers and upper limb pain especially in paraplegics who use manual wheelchairs also increased (Hitzig *et al.*, 2010). Another secondary condition that affects individuals with a SCI and ultimately QOL is chronic pain (Table 6).

**Table 6: Secondary conditions: Chronic pain, fatigue and depression**

Condition	Prevalence	Reference
<b>Chronic pain</b>	Affects 65% of PWaSCI with about a 1/3 of people reporting pain as severe.	Hammell (2010)
	Subjective pain varies from 64-80% with 47% of patients reporting the onset of pain within the first year post injury.	Chiodo <i>et al.</i> (2007)
	Affects mood, function and QOL and ADL.	Hammell (2010) and Chiodo <i>et al.</i> (2007)
<b>Fatigue</b>	Affects between 57-74%.	Hammell (2010)
<b>Depression</b>	Common amongst PWaSCI and during inpatient rehabilitation it affects 20-43% of people. 25-30% of PWaSCI remain depressed after discharge. 30% shows signs of elevated anxiety post discharge.	Hammell (2010)

Pain and the severity of pain experienced by a patient with a SCI are dependent on the completeness of the injury, depression and unemployment. It is not associated with the level of injury. Pain can persist throughout life and is associated with depression, interference with activities, family and social difficulties and with perceptions of diminished QOL (Hammell, 2010).

Fatigue also interferes with physical function, the ability to participate in daily activities and thus ultimately affects QOL. Also related to depression within this population is the high levels of mortality (Hammell, 2010). Although depression is not related to the level of the lesion or the degree of physical independence, it is correlated with pain, feelings of helplessness, anxiety, poor quality of sleep, fatigue and a sense of hopelessness. Hence depression following a SCI is related to decreased participation in enjoyable as well as routine daily activities, decreased social and community intergration as well as decreased QOL (Hammell, 2010).

Musculoskeletal issues are another common secondary condition and include the loss of bone mineral density (BMD), fractures and overuse injuries. These issues are summarised in Table 7.

**Table 7: Secondary conditions: Musculoskeletal injuries**

Condition	Prevalence	Reference
<b>Osteoporosis</b>	61% of men met the criteria for osteoporosis with 19.5% being osteopenic and 19.5% had normal BMD.	Lazo <i>et al.</i> (2001)
<b>Fracture</b>	34% of PWaSCI sustain a fracture	Chiodo <i>et al.</i> (2007)
<b>Upper extremity pain</b>	75% occur in shoulders, 53% in wrists, 43% in hands and 35% in the elbows. 42% of people report that they have pain and 22% rate their pain as severe.	Chiodo <i>et al.</i> (2007)
<b>Shoulder injuries</b>	Common secondary complication after a SCI especially in people with tetraplegia. Range from 30%-70% in PWaSCI, with 75% of individuals presenting with impingement syndromes and 65-71% with rotator cuff tears.	Mulroy <i>et al.</i> (2011)

Shoulder injuries/ shoulder pain affects PA levels, ADL and ultimately quality of life (QOL) (Mulroy *et al.*, 2011). The shoulder joint is particularly vulnerable due to its functional anatomy (highly mobile joint) and limited muscle mass (van Drongelen *et al.*, 2006).

Most studies on shoulder pain are retrospective in nature and few have focussed on inpatient rehabilitation and shoulder pain. Musculoskeletal pain during inpatient rehabilitation plays a crucial role to progress and the duration of rehabilitation (van Drongelen *et al.*, 2006). However, musculoskeletal pain develops relatively quickly during and after the rehabilitation process, which indicates that pain is not only due to overuse. According to van Drongelen *et al.* (2006) musculoskeletal pain may also occur due to adaptation after the injury, which could lead to overuse injuries in the future. In their study shoulder pain was significantly increased during the first three months of active rehabilitation and is due to the subjects becoming dependant on their upper extremities. This is due to the fact that the upper extremities are not well trained in the early phases of rehabilitation (van Drongelen *et al.*, 2006). As the individual undergoes muscle strength training and gains more experience with arm exercise, pain could diminish. It is therefore important that PWaSCI have access to facilities where they can be physically active as increased independence, more frequent performance of ADL's in a less adjusted environment, and less specific muscle training affects shoulder pain post discharge.

As briefly mentioned in table 7 by Mulroy *et al.* (2011), lesion level is also correlated with shoulder pain and individuals with a high level lesion are at a higher risk for musculoskeletal pain in the upper extremities. This is due to paralysis of the thoracohumeral muscles and shoulder muscle imbalances (van Drongelen *et al.*, 2006). Muscle paralysis influence the remaining muscles in that these muscles now have to stabilise the joints and produce the external force to complete a set task or movement (van Drongelen *et al.*, 2006). Individuals with tetraplegia also require additional support to help stabilise the trunk and balance. In the study by van Drongelen *et al.* (2006), most of the subjects with lesion level C6 or C7 performed ADL's independently, and the extra muscle force needed to perform these ADL's could have been responsible for the higher incidence of overload injuries of the upper extremities. Shoulder instability due to muscle paralysis could also contribute to shoulder complaints; however, instability might have contributed to the earlier onset of complaints in subjects with higher lesion levels (van Drongelen *et al.*, 2006).

Musculoskeletal pain in general is experienced during ADL, especially during weight bearing tasks such as transfers and weight relief lifts, where the compression forces around the shoulder joint are high (van Drongelen *et al.*, 2006). For the above mentioned, balance is also crucial. More than 25% of the person's body weight is transferred through the humerus to the thorax during the execution of such tasks. Pain could be due to shoulder impingement, which is caused by the reduction in the subacromial space and the supraspinatus muscle being impinged between the coracoid and acromion process (van Drongelen *et al.*, 2006). How damage to these structures take place is unknown, however, the investigators did find that both muscle strength and functional outcome were inversely related to shoulder pain (van Drongelen *et al.*, 2006). The shift in load together with the repetitive nature of manual wheelchair propulsion lead to fatigue in the upper extremities, which may predispose the shoulder to shoulder pain, shoulder impingement and musculotendinous injuries (Mulroy and Perry, 2004). According to van Drongelen *et al.* (2006), it is evident that manual wheelchair propulsion and wheelchair related daily activities place a heavy load on a person's upper extremities. Chiodo *et al.* (2007), also mentioned that transfers and pressure relief also contributes to overuse injuries and ultimately shoulder pain. Other factors identified as a risk for shoulder pain include the duration of injury, age (older people have a higher risk), higher BMI and wheelchair propulsion style (van Drongelen *et al.*, 2006). Chiodo *et al.* (2007) also mentioned that time since the injury, limitations in shoulder ROM, acromioclavicular joint narrowing, rotator cuff muscle imbalances and adductor weakness, anterior muscle tightness with posterior muscular weakness, lower overall health and lower function to be associated with shoulder pain.

It is clear that shoulder pain is inevitable following a SCI, if proper care is not taken. Therefore van Drongelen *et al.* (2006), suggested that a specific exercise protocol be followed which consists of stretching and strengthening of the shoulder muscles as it could decrease upper extremity pain. During the beginning phases of in-patient rehabilitation, care should be taken to prevent overload (performing heavy ADL like transfers). Van Drongelen *et al.* (2006) suggested that together with weight gain prevention, rehabilitation should focus on balanced training of the upper extremities to make up for the arrears in strength of the upper limbs. According to Scelza *et al.* (2007), overuse injuries in the shoulder should be prevented and should be a part of the exercise regimen. It was suggested by Scelza *et al.* (2007) to vary the activities as much as possible in order to avoid common overuse injuries, as well as provide strengthening activities to all the major muscle groups where possible. According to Mulroy *et al.* (2011), shoulder pain leads to additional losses in function and community mobility without an intervention. Nawoczinski and Ludewig (2006) also found that after a specific home stretching and strengthening program was followed, shoulder pain was reduced, and there were significant improvements in shoulder function.

According to van Langeveld *et al.* (2011), physical therapy, occupational therapy and sports therapy collectively contribute to improved physical performance and capacity in relation to mobility and self-care in PWaSCI. Mobility covers sitting, standing, transfers, wheelchair mobility and transportation. Self-care covers eating, drinking, washing, caring for body parts, dressing and toileting. This cross cultural study was conducted in Australia, Norway and the Netherlands and showed that the same amount of time was spent on different aspects of rehabilitation. In all the countries most of the time was spent on exercise interventions for mobility and self-care at the levels of body functions and basic activities. Little time was spent on practicing skills in task orientated and context specific activities (outside the exercise room, at the complex activity level), or on other types of interventions (equipment and education) (van Langeveld *et al.*, 2011). This further stresses the point that health care professionals do not necessarily focus on the final outcome of the rehabilitation process as was discussed in section 2.2.2. They may only be focussing on getting the person to the point where they can be discharged with just sufficient strength and coping abilities, but which may not be enough to manage and cope within their respective communities.

Secondary health conditions seem unavoidable, however, certain precautions can help reduce the occurrence of such conditions and include; the use of appropriate pressure relief cushions, proper positioning and balancing to avoid falls and risk of fractures (Scelza *et al.*, 2007). Sport can also help avoid secondary conditions and it may also help to improve the QOL of the individual, especially since PWaSCI have a poorer QOL than their able bodied

counterparts (Kehn and Kroll, 2009). Kehn and Kroll (2009) also found that paraplegic individuals who participated in sport were more successful in avoiding secondary conditions and further hospitalisations than those individuals not participating in sport. The authors also identified that the most important predictor of QOL was a reduction in secondary conditions and secondly engagement in PA and sport. Knowledge about upper extremity complaints, which include their course and prognostic determinants are also important. Not only to predict the condition at the end of their rehabilitation period, but also, for treatment and prevention of future pain (van Drongelen *et al.*, 2006). Rehospitalisation due to SHC often occurs due to a lack of knowledge and training, and it is, therefore, imperative that patients receive the right information and skills to cope with these conditions.

### 2.3.1. **Rehospitalisation**

Rehospitalisation mainly occurs due to secondary complications. Secondary complications following a SCI are common as seen in section 2.3 and hospital admissions are costly. Table 8 on the following page summarises the most common secondary conditions that lead to rehospitalisations.



**Table 8: Rehospitalisations due to secondary conditions**

<b>Condition</b>	<b>Prevalence</b>	<b>Reference</b>
<b>Osteoporosis, cardiovascular disease, pressure ulcers, urinary tract infections, diabetes and arthritis.</b>	/	Cardenas, Hoffman, Kirshblum and McKinley (2004)
<b>Genito-urinary complications and pressure ulcers</b>	Most common in people with a complete injury	Chiodo <i>et al.</i> (2007) and DeJong <i>et al.</i> (2013)
<b>Respiratory complications (Pneumonia)</b>	Most common in people with tetraplegia	
<b>Pressure ulcers</b>	26.4% superficial wound; 19.8% redness of skin; 12.8% deep wound	Bloemen-Vrencken <i>et al.</i> (2005)
<b>Urinary tract infections</b>	45.6%	
<b>Respiratory infections</b>	7.5%	
<b>Pressure ulcers</b>	78%	Mothabeng (2011)
<b>Leading reasons during the first year of injury:</b>		
<b>Urinary tract infections</b>	17%	Davidoff <i>et al.</i> (in Dryden <i>et al.</i> , 2003)
<b>Deep vein thrombosis</b>	12.8%	
<b>Respiratory complications</b>	19%	
<b>Urinary tract infections</b>	14%	
<b>Dermatological conditions</b>	7%	Meyers <i>et al.</i> (1985)

As seen from the above mentioned table, the most common secondary conditions leading to rehospitalisations include respiratory infections, urinary tract infections and pressure sores. Not much research has been done as to why these secondary conditions occur, however, Dini, Bertone and Romanelli (2006) mentioned that pressure ulcers are mainly caused by inactivity and prolonged pressure caused by sitting. Below the level of injury most or all sensation is lost and the brain no longer receives messages that the area has been injured by, for example, prolonged sitting (Mayo Clinic, 2015b). Respiratory conditions (pneumonia) are more common in individuals who have cervical or thoracic lesions where the breathing mechanism is affected. In individuals where the abdominal muscles, diaphragm and chest muscles are affected, it is more difficult for the individual to breathe or cough (Mayo Clinic, 2015b).

Rehospitalisation also seems to be correlated to the time since injury. According to Cardenas, Hoffman, Kirshblum and McKinley (2004) it occurs most frequently within the first year of initial release, and as post injury time increases rehospitalisation becomes less frequent. Other authors suggested that re-admissions occur most frequently in the first three to five years and decreases thereafter (Dryden *et al.*, 2003). DeJong *et al.* (2013) indicated that individuals with traumatic SCI have higher rates of unplanned rehospitalisation and often for conditions that are preventable.

In South Africa it was found that rehospitalisation occurred soon after discharge, and was mainly attributed to the fact that people were not coping with their injury (SCI) in their communities, and more specifically with healthy living (Mothabeng, 2011). This leads to many questions pertaining initial rehabilitation and adequate assessment before discharge. In the study conducted by Mothabeng (2011), 48% of the participants were re-admitted due to one or more secondary complication associated with a SCI. Cardenas *et al.* (2004) also found that decreased functional abilities at discharge affect rehospitalisations, along with the extent and neurological level of injury. This emphasises the fact that there is a gap between inpatient rehabilitation and health and wellness post discharge that needs to be filled. Once patients are readmitted, additional therapy is often required to regain strength, endurance and physical function which may be lost whilst rehospitalised. Being readmitted to hospital can be very disruptive, undermine rehabilitation gains and also diminish an individual's ability to live actively and independently as possible (DeJong *et al.*, 2013). According to Meade, Forchheimer, Krause and Charlifue (2011), rehospitalisation and secondary conditions are also associated with reduced odds of job retention and acquisition. According to Dryden *et al.* (2003), these also interrupt work, education and interpersonal relationships and this may affect QOL.

According to DeJong *et al.* (2013), patient education plays a major role in preventing these medical conditions, however, the process is not that straight forward. Longer hospital stays are also associated with decreased odds of rehospitalisation. Rehabilitation provides time for both patients and staff to manage underlying medical conditions, and reducing rehabilitation time could lead to patients not being adequately tested for secondary or other medical complications, leading to rehospitalisation within the first year post discharge (DeJong *et al.*, 2013). In general a SCI places an enormous burdon on health care systems and PWaSCI in general have higher contact rates with health care systems when compared with the general population. These contacts with health care systems include hospitilisations, long term care admissions, home care services and physician contacts (Dryden *et al.*, 2003).

## 2.4. Quality of Life and Physical Activity within SCI patients

### 2.4.1. Quality of Life

It was not until the late 20<sup>th</sup> century that life expectancy for a PWaSCI was increased. This was mainly attributed to the fact that primary care was neglected and secondly due to the mismanagement of secondary complications after a patient was released from hospital (Norrbrink *et al.*, 2007). According to Sadowsky *et al.* (2002) and Whiteneck *et al.* (2009), the life expectancy of those injured within the last decade and those who will be injured in the future, is predicted to be near that of the general population. This is mainly due to improved emergency and long term management techniques (Scelza, Kalpakjian, and Zemper and Tate, 2005). Adjustment to a SCI is an important factor to consider as it ultimately affects QOL and life satisfaction. According to Lee and McCormick (2004), a higher QOL, life satisfaction and subjective well being is associated with increased levels of quality and richness of social contacts. In PWaSCI subjective well being and life satisfaction are related to community functioning and social interactions, and not level of injury and functional independence (Lee and McCormick, 2004). Successful transition back into society and establishing a satisfying life, is dependent on one's ability to enjoy leisure time, since social interaction and community activities often occur in a leisure context (Lee and McCormick, 2004).

Recent research has focussed on the QOL as a key outcome in determining the efficacy of rehabilitation (Devillard *et al.*, 2007; Stephens, Neil and Smith, 2012). It was suggested that health promotion and increased PA may improve QOL and life satisfaction in PWaSCI (Stephens, Neil and Smith, 2012). Tasiemski *et al.* (2004b) compared two different groups (control vs PA group) with the outcome measure being life satisfaction in PWaSCI. The results showed that the group who participated in recreational sports and PA had higher life satisfaction than the group who did not participate in PA. These results are in agreement with previous literature that found statistically significant relationships between community integration and life satisfaction (Dijkers, 1999; Chun, Lee, Lundberg, McCormick and Heo, 2008). Malone *et al.* (2012), also found that PWD also report lower scores for health status and QOL when secondary conditions are present.

Very few studies have evaluated the adjustment to a traumatic SCI and one possible reason for this could be that the coping process for each individual is unique and dependent on several factors (Stensman, 1994). The variables related to the coping processes among PWaSCI include; age of onset, duration of disability, gender, background of the trauma,

social situation, level of injury, physical problems including pain, personality including sensation seeking behaviour and locus of control (Stensman, 1994). According to Norrbrink *et al.* (2007), age also plays a role in survival. People who sustain their injuries in their teens and twenties have a higher survival rate than people in older age groups. Although the final outcome can never be predicted, mitigating the effects of aging with appropriate lifestyle changes can have an effect. Stensman (1994), found that if individuals were older than 35 years at the onset of the disability, adjustment is more problematic. This is due to the fact, that as individuals get older, there is a loss of energy and it also becomes more difficult to adjust to changes that happen in life. Another factor that contributes to adjustment after a SCI includes education. It was found in earlier studies that people with less education, scored lower in adjustment variables compared to more educated individuals (Stensman, 1994). It was also noted that the first half year after the injury was the most difficult. Although most of the findings were negative and related to bladder and bowel problems, most of the participants also mentioned positive aspects. The positive aspects included the importance of good relationships with family and friends, while the lesion level did not seem to influence the adjustment to the injury.

Survival following a SCI has improved considerably and persons now have an increased life expectancy, which extends into the sixth and seventh decade (Livecchi, 2011). Due to the increased life expectancy PWaSCI are at an increased risk of developing other health conditions associated with the aging process. Although PA is an essential component in enhancing health, the onset of a physically disabling condition such as a SCI, can provide serious challenges (Kehn and Kroll, 2009). The first obstacle in achieving an active lifestyle is the loss of volitional motor control, muscle weakness and loss of sensation that accompanies a SCI, which leads to PWaSCI being hypoactive (Jacobs and Nash, 2004) and which in turn affects their physical capacity and ultimately QOL. It is therefore important to measure QOL subjectively in order to understand how their QOL can be improved by addressing the abovementioned concerns.

#### **2.4.2. Quality of Life and Measurement of Quality of Life**

According to Reabum and Rootman (1996) (in Lee and McCormick, 2004), QOL is a representation of how good life is and according to Hammel (2010) the individuals' satisfaction with their lives and their overall sense of well being. Chun *et al.* (2008) highlighted the importance of the individual's life satisfaction with major aspects of daily functioning as important indicators of subjective QOL. Measuring QOL is important, especially in conditions where cure is not an option and therapy becomes lifelong (Wood and Williams, 1987). Therefore, the authors suggested that reintegration to normal living be

assessed. When return to a pre- injury lifestyle is attained, it is easier for individuals to reorganize their lives and achieve “harmony.” But when the disease or disability is permanent, adjustment is more difficult. It not only involves accepting the injury, but for some also accepting the prospects of lowered life expectations (Wood and Williams, 1987). Therefore QOL for individuals with disabilities have been considered an important issue in the healthcare field and is one of the major goals/outcomes for PWD (Chun *et al.*, 2008).

According to Hitzig, Escobar, Noreau and Craven (2012) most assessment tools available for the SCI population are objective and include the widely used Craig Handicap Assessment and Reporting Technique (CHART). The CHART evaluates five areas and include; physical independence, mobility, occupation, social integration and economic self sufficiency. The information gathered is also compared to that of able bodied individuals and how they fulfil these roles. Limitations include the fact that it does not take the individual’s social network and quality of support into consideration and it assesses more the “handicap” and not participation (Hitzig *et al.*, 2012).

Other subjective assessment tools that can be used to assess participation after a SCI include; Impact on Participation and Autonomy (IPA) Questionnaire, Assessment of Life Habits (LIFE-H) and Participation Survey/Mobility (PARTS/M). Most of these questionnaires carry a high administrative burden and some have not been widely used within the SCI population. The Reintegration to Normal Living Index (RNL Index) can also be used to subjectively measure participation after a SCI, as it assesses the QOL of PWD (Stark, Edwards, Hollingsworth and Gray, 2005). The index is an 11 item instrument, which was designed to assess personal satisfaction with performance of everyday activities. The index covers the following areas; involvement in recreational and social activities, self care, perceived ability to move within the community and the degree to which people are comfortable with the roles they have in their family and other relationships (Stark *et al.*, 2005; Hitzig *et al.*, 2012). The RNL Index has a low administrative burden and it is a brief questionnaire. It can also be used to assess community dwelling chronic SCI populations and their participation after a SCI. The index is also shown to have good internal consistency and validity (construct/concurrent) (Hitzig *et al.*, 2012).

### 2.4.3. **Community Participation and Reintegration**

According to De Wolf, Middleton and Cameron (2010), definitions regarding community integration vary but common associations include relationships with others, independence in ADL and spending time meaningfully. A definition associated with the SCI population states:

“Resuming age/gender and culturally appropriate roles/statuses/activities including independence/interdependence in decision making and productive behaviours performed as part of multi-varied relationships with family, friends and others in natural community settings.” (De Wolf *et al.*, 2010:1185)

In Forchheimer and Tate (2004) it is said that community living is one where a person contributes to every aspect of community life and this includes making a contribution to economic and political life, as well as engaging in social and cultural pursuits. A contribution is made to economic and political life through employment and civic action and engaging in social and cultural pursuits, includes partaking in recreation, sports, community enrichment and other leisure activities. Community participation or integration (successful engagement in occupational, social and community activities) is considered an important factor in predicting QOL, as well for the experience of life satisfaction (Chun *et al.*, 2008).

For PWaSCI reintegration is an issue, since a SCI often happens to people who are physically healthy, active and already integrated into a social life (Forchheimer and Tate, 2004). However, once the inpatient phase of rehabilitation is completed, people are discharged and its during this time that most PWaSCI face many obstacles in resuming their normal social roles (Forchheimer and Tate, 2004). The goal of rehabilitation is to assist with this process of reintegration back into society and the person’s previous roles and relationships. Community re-integration after hospitalisation is an important outcome of initial rehabilitation (Forchheimer and Tate, 2004). These outcomes include restoring the patient’s independence, QOL, self sufficiency and greater control over their lives and this cannot be achieved by medical rehabilitation services alone (Forchheimer and Tate, 2004). Once discharged patients are suddenly left on their own with the responsibility of complete control over their health care and other important life decisions.

“Community re-integration includes physically getting to places that are not adequately accessible, as well as taking responsibility for maintenance of the various technologies that facilitate community activity.” (Forchheimer and Tate, 2004:103)

It also involves participating in activities that might have been different pre-injury.

“Community re-integration, thus, connotes overcoming the many barriers imposed by one’s disability and the surrounding environment.” (Forchheimer and Tate, 2004:104)

According to Forchheimer and Tate (2004) maintaining health and avoiding secondary complications after a SCI is important, however, PWaSCI must also learn how to adjust to their changed roles within their families, jobs and communities. The above definitions illustrate what community reintegration is about, but one aspect that is not mentioned is the attitudes of community members and of society that impacts the ability of PWD to be accepted and integrated into society (Monk and Wee, 2008). The attitudes of community members can affect integration by influencing self efficacy and by influencing the physical and social environment of PWD (Monk and Wee, 2008). According to Monk and Wee (2008) community attitudes are important especially for the success of a community based rehabilitation (CBR) program. The authors stated that the community should be involved in all the steps of the process, including program planning, implementation and evaluation.

Over the past three decades, there has been a considerable improvement in the medical, technological and pharmacological management of SCI (Magasi, Heinemann and Whiteneck, 2008). This has led to PWaSCI living longer and achieving greater functional independence. Hence rehabilitation has changed its focus from medical management of acute conditions to the issues that affect QOL and community participation (Magasi, Heinemann and Whiteneck, 2008). Mothabeng (2011) discovered that various factors play a role in community participation in South Africa and include; personal factors, disability related factors and environmental factors. Personal factors included race, level of education, residential area and employment (related to the socioeconomic status of the participants). Disability related factors included, years living with a SCI, perceived health (readmission to hospital) and functional ability (level of SCI). Environmental factors included, access around the home and community and transportation. Another relevant theme identified by Mothabeng (2011) is personal needs and includes education, the need to exercise, the need to be independent and the need for employment. Individually and collectively these factors also play a role in community participation. Mothabeng (2011) also suggested that follow up care is important to ensure that patients do not develop secondary complications after discharge and to ensure maximal participation and community reintegration.

Regular PA has many physical and psychological benefits and it also has social benefits; it helps to establish new friendships, experiences and helps to develop social networks thereby reducing the “handicap” (Tasiemski *et al.*, 2004a). Sports participation also helps to aid community integration and improves family relationships (Tasiemski *et al.*, 2004a). It is therefore important that PWaSCI participate in PA in order to successfully reintegrate into their families and communities. This is reiterated by Devillard, Rimaud, Roche and Calmels (2007) that reconditioning programs have a good impact on QOL, which permits an increase

in participation in PA and ADL in PWaSCI. However, according to Rimmer and Henley (2013:72) many people will return home after hospitalisation with few, if any, options to continue their “structured recovery.” According to the authors, if adjusting to a life after a neurologic disability is not harmonized by the community’s receptivity in helping reintegration and partaking in PA and wellness, re-engagement becomes particularly difficult. This statement just emphasises the problem, namely, there is lack of implementation of community based PA programs versus the amount of research that is done stating that PA is important and necessary in this population.

#### 2.4.4. **Physical Activity**

According to the Centre of Disease Control (CDC) (2011) regular PA is one of the most important things you can do for your health. It can help with weight control, reduce the risk of cardiovascular disease, type II diabetes, metabolic syndrome, and some cancers. It can strengthen bones and muscles, improve mental health and mood, improve the ability to complete ADL, prevent falls in older adults and increase the chances of living longer (CDC, 2011).

PA, exercise and physical fitness are terms that are often used interchangeably throughout research. These terms, however, describe different concepts (Caspersen, Powell and Christenson, 1985), although they also overlap somewhat. PA and exercise both involve bodily movement using skeletal muscles, which results in energy expenditure. The latter may vary from low to high and is positively correlated with physical fitness as intensity, duration and frequency of movement increases (Caspersen, Powell and Christenson, 1985). Additionally, exercise is perceived as planned, structured and repetitive bodily movements with the objective to improve or maintain one or more components of physical fitness (ACSM, 2013). Throughout this text PA, exercise and sport has mainly been used to describe a variety of activities and was at the discretion of the researcher. For the purpose of this research, the researcher prefers to use the term PA as it is related to activities that impact health and wellness, without the explicit goal to improve physical fitness.

According to ACSM (2015) health and PA are closely linked and the more days you are active the higher the value for your health and wellness. This is particularly important in people who are inactive. Leisure activities are also considered to be a part of health and wellness and leisure constitute an important part of life for PWD (Crawford and Stodolska, 2008) and is also considered part of PA (Caspersen, Powell and Christenson, 1985). For some individuals leisure is passive relaxation and for others it is actively engaging in PA. During rehabilitation, sport may even be used as a tool to introduce PWD to sports, however,



very few people actually stay active after they finish with their rehabilitation (van der Ploeg and van Mechelen, 2004). Physical inactivity makes PWaSCI even more prone to chronic conditions.

The CDC (2011) also stated that everyone can gain health benefits from PA, no matter their age, ethnicity, shape or size. In PWaSCI deconditioning is evident and leads to other medical complications (Ginis *et al.*, 2011) such as diabetes mellitus, heart disease, arterogenic lipid profiles and hypertension. Deconditioning is affected by a sedentary lifestyle, which itself can lead to a series of physical and cardiovascular complications in PWaSCI (Devillard *et al.*, 2007; Ginis *et al.*, 2011). According to Devillard *et al.* (2007) the usual daily activities of PWaSCI are considered inadequate to maintain fitness and therefore may affect QOL as well. The lack of participation in PA programs in this population may lead to reduced self sufficiency and also an increased risk for cardiovascular disease (Devillard *et al.*, 2007). According to Scelza *et al.* (2005) cardiovascular health is a major concern for those individuals living with a SCI, since heart disease has been found to be one of the major causes leading to death. According to Myers, Lee and Kiratli (2007), individuals with a long term SCI are more likely to have morbidity or mortality from cardiovascular disease than from renal and pulmonary conditions, which were the primary causes of mortality in previous decades. According to Vuori, Lavie and Blair (2013) PA (particularly energy expenditure) is necessary to prevent the development of various diseases, including cardiovascular disease. The daily energy expenditure within this population is in general lower when compared to ambulant individuals and this is not only due to a lack of motor function, but also due to lack of accessibility and fewer opportunities to partake in regular PA (Myers, Lee and Kiratli, 2007). These problems collectively affect activities of daily living (ADL), QOL and contribute to accelerated aging (Jacobs and Nash, 2004; van den Berg-Emons, 2008).

According to Myers, Lee and Kiratli (2007) recent studies have also shown that the metabolic and skeletal muscle abnormalities that occur following a SCI can be partially reversed through endurance training with upper body arm ergometry, functional electrical stimulation (FES) of the lower limbs or with a combination of the two. Peak oxygen consumption ( $VO_2$ ) has also shown to be increased through PA to levels similar to that of ambulatory individuals. These increases are, however, inversely proportional to the level of injury. Lipid profiles have also been shown to be favourably affected by PA in SCI individuals (Myers, Lee and Kiratli, 2007).

Within the general population, exercise has shown to improve functional capacity, endurance, muscle strength, psychological well being, as well as contribute to the reduction

of stress (Scelza *et al.*, 2005; van Langeveld *et al.*, 2011). According to Wahman, Biguet and Levi (2006) it is also known that PA performed by PWaSCI (and persons with other mobility problems) has beneficial effects on stamina, strength and the ability to manage ADL and psychological well being. Current research has also shown that exercise after a SCI counteracts some of the effects of the lesion (Gomez-Pinilla, Ying and Zhuang, 2012). Fekete and Rauch (2012) stated that PA in PWaSCI is also associated with lower depression and anxiety scores, increased life satisfaction and enhanced social integration. Levins, Redenbach and Dyck (2004) showed that with endurance training, PWaSCI can achieve exercise performance (with reference to cardiovascular and respiratory function) similar to individuals without known pathology or impairments.

Van den Berg-Emons *et al.* (2008) evaluated the PA levels in PWaSCI and whether PA was adhered to after initial rehabilitation. They found that during inpatient rehabilitation PA was increased, however, shortly after discharge from the rehabilitation centre there was a decline in duration of dynamic activities. According to the authors this was probably due to the fact that PWaSCI do not have all their mobility aids and adaptations at their houses at the time of discharge. However, at one year after discharge the duration of activity levels was restored to the same level as at initial discharge. However, their duration levels, activity time were still considerably lower than those of able bodied individuals as well as in persons with other chronic diseases, such as individuals with hemiplegic cerebral palsy, chronic heart failure and leg amputations (van den Berg-Emons *et al.*, 2008). The participants were also not considered healthy as they did not meet the minimum exercise recommendation guidelines as prescribed by the American College of Sports Medicine (ACSM). According to van den Berg-Emons (2008) age plays a role during inpatient rehabilitation. In older persons recovery was slower and because of their age they may or may not have other co-morbidities. After discharge the completeness of the injury and the lesion level determined PA levels. In persons with an incomplete lesion and paraplegia there was a greater improvement in PA levels when compared to persons with tetraplegia and complete lesions (van den Berg-Emons *et al.*, 2008).

Although the benefits of PA are evident there remain physiological, psychological and environmental barriers to exercise for PWaSCI. The lack of exercise opportunities (environmental barrier) also contribute to a sedentary lifestyle within this population (Jacobs and Nash, 2004). Not ignoring the physical limitations that a person with a SCI faces, they can still undergo reconditioning (Jacobs and Nash, 2004). With rehabilitation, patients with a SCI are able to return quickly to their ADL and maintain adequate fitness with the basic aim being to reduce the effects of the lesion and a sedentary lifestyle (Devillard *et al.*, 2007).

Although the level of sport and active leisure participation is important in rehabilitation and long term care, participatory hours are still reduced after a SCI as well as the number of people who remain active after such an injury (Stephens, Neil and Smith, 2012). According to Foulon *et al.* (2012), 50% of PWaSCI do not participate in any form of leisure time PA due to a lack of evidence based PA guidelines.

#### 2.4.5. Physical Activity and Exercise Recommendations

Promoting PA is difficult in the absence of information regarding the type of exercise, as well as the amount and intensity that yield meaningful benefits (Ginis *et al.*, 2011). It is important that an individual adheres to certain exercise criteria in order to meet the minimum standard to attain health and wellness. According to ACSM (2015) lead author on ACSM/AHA guidelines, Dr. Haskell, guidelines for PA have long been based on research and demonstrated that even relatively moderate amounts of PA can have positive effects on health. However, in the U.S.A., 56% of persons without disabilities meet the national PA guidelines compared to 36% of PWD (Rimmer *et al.*, 2004). Additionally, 25.6% of PWD are reported to live sedentary lifestyles (Rimmer *et al.*, 2004). Hence PA guidelines would thus be very beneficial for clinicians and exercise programmers in designing effective programs.

According to ACSM (2010) the exercise recommendations for PWaSCI are consistent with that of able bodied individuals and is summarised in Table 9.

**Table 9: ACSM (2013) exercise recommendations for able bodied individuals**

Exercise	Frequency (day/week)	Intensity	Duration (min)
Cardiovascular	3-5	40-90% VO <sub>2</sub> R	20-60
Strength	2-4	2-3 sets of 12 reps	

More current research done by Ginis *et al.* (2011) suggested that the able bodied guidelines are not necessarily appropriate for PWaSCI and that the development of PA guidelines for this population is long overdue. The authors sought to tailor PA guidelines that are specific to the needs and capabilities of PWaSCI. The following guidelines were generated by the expert panel for important fitness benefits for adults with a SCI (Table 10).

**Table 10: Ginis et al. (2011) exercise recommendations for persons with a SCI**

<b>Exercise</b>	<b>Frequency (day/week)</b>	<b>Intensity</b>	<b>Duration (min)</b>
<b>Cardiovascular</b>	2	Moderate to vigorous	At least 20
<b>Strength</b>	2	3 sets of 8-10 reps	

The Spinal Cord Injury Action Canada organization also published the information from table 10 on their website (<http://sciactioncanada.ca/docs/guidelines/Physical-Activity-Guidelines-for-Adults-with-a-Spinal-Cord-Injury-English.pdf>) and currently uses it as guidelines for PA.

Most of the researchers investigated intensity, frequency and duration of PA, however, Buchholz *et al.* (2009) studied the relationship between leisure time PA (LTPA) and common risk factors for cardiovascular disease and type 2 diabetes in community dwelling adults with SCI (Buchholz *et al.*, 2009). They reported that PWaSCI who engage in at least 25 min/day of mild to moderate intensity of LTPA have lower body mass index (BMI), % fat mass (FM), C-reactive protein (CRP) and insulin resistance and higher % fat free mass (FFM) than PWaSCI who do not partake in LTPA (Buchholz *et al.*, 2009). The results of this study supported that of tables 9 and 10, showing that with a minimum amount of activity health benefits can be achieved in PWaSCI.

From the literature above (Tables 9 and 10) there is a clear difference in the daily exercise recommendations for PWD in terms of frequency, intensity and duration. Due to the lack of research in this area it is difficult to say which guidelines or recommendations are more appropriate as all indicated improvements. However, it can be argued that the more PA is performed the greater the health benefits as is seen in the able bodied population. However, due to the constraints and barriers faced by PWaSCI in participating in PA, the guidelines in table 10 might be more achievable in this population and could possibly be considered the minimum recommendation.

Some of the recommendations for cardiopulmonary training in PWaSCI include arm crank ergometry, wheelchair propulsion, swimming, vigorous wheelchair sports, ambulation with crutches or braces, seated aerobic exercise and the use of electrically stimulated leg cycle activities (Scelza *et al.*, 2007). Valent *et al.* (2009) suggested that hand cycling is less strenuous and thus a better mode of exercise when compared to hand-rim wheelchair propulsion, especially in tetraplegics. Persons with tetraplegia also find it difficult to apply a well-directed force during every push in a hand-rim wheelchair and force can only be applied

to 20-40% of the cycle. Furthermore, hand-rim wheelchair propulsion may also lead to upper extremity pain and overuse injuries. With hand cycling, however, the individual's hands are fixed and the person can apply forces over 360° during both the push and pull phases. Hand cycling also results in higher mechanical efficiency and peak power output ( $PO_{peak}$ ) when compared to hand-rim wheelchair propulsion (Valent *et al.*, 2007).

Regardless of the mode of exercise, the goal of the exercise programme should be small, although progressive improvements in strength and endurance should be ensured (Scelza *et al.*, 2007). The expectations in terms of improvements should be based on the amount of muscle mass being exercised; the larger the muscles mass being exercised, the greater the improvement in fitness that can be expected (Scelza *et al.*, 2007).

## **2.5. The Effects of a SCI on Physical Activity**

PA is essential for the development and maintenance of healthy structures and functions within the body (Vuori, Lavie and Blair, 2013). A lack of PA leads to weakness and degeneration and affects aberrations in metabolism that can manifest as functional deficiencies and diseases in a variety of organs (Vuori, Lavie and Blair, 2013). Thus, a hypoactive lifestyle after a SCI has the potential to restrict functional independence and increase the risk for chronic diseases and secondary complications (Washburn, Zhu, McAuley, Frogley and Figoni, 2002). After a SCI cardiorespiratory fitness and muscle strength decreases and this affects physical capacity (Pelletier, 2013). This may be due to the changes in autonomic function that take place after a SCI.

### **2.5.1. Autonomic Function**

In order to understand certain PA responses in PWaSCI, autonomic function needs to be understood, especially since autonomic function impacts physical capacity which in turns affects PA. Autonomic function (heart rate and blood pressure) is affected by a SCI and the severity of dysfunction is related to the level and the completeness of the injury (Sisto *et al.*, 2012). In a PWaSCI heart rate (HR) and blood pressure (BP) are affected and results in a blunted response during exercise as well as heart rate recovery (Sisto *et al.*, 2012) and diminished physical capacity (Jacobs and Nash, 2004). The appropriate heart rate and blood pressure regulation and reflex responses are important aspects in cardiovascular control as it affects performance and can hinder the post acute phase of rehabilitation and ADL (Myers *et al.*, 2007; Sisto *et al.*, 2012). A disruption in autonomic function leads to an interruption in cardiovascular homeostasis, for example, in people with cervical lesions maximal heart rate may be reduced to 110-130 beats/min (Devillard *et al.*, 2007; Myers *et al.*, 2007). In persons with tetraplegia the impaired sympathetic nervous system may cause bradycardia,

orthostatic hypotension, autonomic dysreflexia, temperature dysregulation and sweating disturbances. Cardiovascular problems associated with autonomic dysfunction include two particular conditions, namely orthostatic hypotension and autonomic dysreflexia. Both of these conditions affect performance and hinder the completion of ADL.

Orthostatic hypotension is a condition seen in SCI patients in the acute as well as chronic stages of the injury (Sisto *et al.*, 2012). In general PWaSCI have low arterial blood pressure due to the reduced sympathetic nervous system activity below the lesion level (Myers *et al.*, 2007). Orthostatic hypotension occurs when changing body position, from the supine to the upright position (Sisto *et al.*, 2012). It is defined by a drop in systolic blood pressure of 20 mmHg and/or a drop in diastolic blood pressure of 10 mmHg. A drop in blood pressure mainly occurs because the redistribution of blood flow to the active muscles does not occur due to the attenuation of peripheral vascular resistance.

Autonomic dysreflexia is more life threatening than orthostatic hypotension and is common in PWaSCI with a lesion at or above T6. Autonomic dysreflexia is caused by noxious stimuli below the lesion level. These stimuli could be caused by a distended bladder, spasms, bladder catheterization (Pelletier, 2013), bone fractures, thromboembolism and sudden temperature change (Jacobs and Nash, 2004). The presence of one of these stimuli causes an imbalanced reflex sympathetic discharge and peripheral vasoconstriction, which leads to hypertension (Jacobs and Nash, 2004). The brain tries to rectify the situation, but due to the lack of spinal cord continuity, the descending inhibitory responses only travel as far as the lesion level and uncontrolled hypertension remains.

### 2.5.2. Physical Capacity

Physical capacity is typically defined in terms of peak oxygen uptake ( $VO_{2peak}$ ) and peak power output ( $PO_{peak}$ ) and is measured during maximal exercise tests (Pelletier, 2013).

“Physical capacity is the combined ability of the cardiovascular, the respiratory, and the musculoskeletal systems to attain a certain level of activity.” (Haisma, 2006:741)

Physical capacity influences functional ability, wheelchair skills performance, ADL and return to work (Pelletier, 2013). It is therefore important to consider physical capacity and the potential effects it has on health status (increased risk of complications) and QOL in PWaSCI (Haisma *et al.*, 2006). Especially during the first month of inpatient rehabilitation when physical inactivity is high because of long periods of bed rest (Kilkens, Dallmeijer, van Nene, Post and van der Woude, 2005). Physical capacity ultimately affects the ability to

perform PA and therefore health. Physical capacity is affected in PWaSCI and subsequently reduced due to muscle weakness, loss of autonomic control below the lesion level, reduced activity and the changes that take place in metabolic and vascular function (Haisma *et al.*, 2006). Physical capacity has different components that are influenced by personal and lesion related factors and also by training (Janssen, Dallmeijer, Veeger and van der Woude, 2002; Haisma *et al.*, 2006). These factors include power output, oxygen uptake, muscle strength and respiratory function. According to Myers *et al.* (2007) there is a strong inverse relationship between the level of injury and  $VO_{2peak}$ . The assessment of cardiorespiratory fitness is therefore essential for rehabilitation and sports performance evaluation (Vanderthommen *et al.*, 2002) and especially for the design of effective interventions.

In PWaSCI there is a greater reliance on the upper body to perform activities, which in turn does not reflect whole body physical capacity. This is mainly due to the smaller muscle mass and the loss of sympathetic control (Devillard *et al.*, 2007; Pelletier, 2013) that is available to perform the activity. The severity and location of the injury largely determines the individual's capacity for exercise and disturbances in cardiovascular control are evident in all individuals with SCI, especially in those with tetraplegia (Valent *et al.*, 2007). The low physical capacity in people with tetraplegia is attributed to extensive muscle paralysis, which results in a reduction of function in the arms, trunk and legs. The reduced venous return and impaired sympathetic cardiac regulation contribute to the limited exercise capacity in people with tetraplegia (Dallmeijer, Hopman, van As and van der Woude, 1996). According to Valent, Dallmeijer, Houdijk, Sloodman, Janssen, Post and van der Woude (2009) physical capacity is also affected by a diminished cardiovascular response to PA and therefore low in persons with cervical lesions. In the study done by Valent *et al.* (2009) the researchers evaluated physical capacity in untrained patients with tetraplegia using structured hand cycling interval training. The results did show significant improvements in physical capacity ( $VO_{2peak}$  (8.7% increase) and  $PO_{peak}$  (20.2% increase)).

According to Haisma *et al.* (2006) physical capacity changes are most prominent during the first phase of inpatient rehabilitation and it is therefore important to determine whether patients are able to maintain and improve their physical capacity post discharge. In the study the researchers used a motor driven treadmill and a graded maximal wheelchair exercise test to test physical capacity. During inpatient rehabilitation  $VO_{2peak}$  (24% increase),  $PO_{peak}$  (41% increase), muscle strength and respiratory function improved especially during the early phase of rehabilitation.  $VO_{2peak}$ , muscle strength and respiratory function also continued to improve after discharge (one year post discharge). Once discharged

participation in physical activity during ADL, outpatient rehabilitation programs and or sporting activities proved to be sufficient to continue to improve physical capacity. This study was significant as physical capacity is related to performance and it is important to determine whether PWaSCI can maintain or improve their physical capacity post discharge. In another study conducted by Dallmeijer, van der Wouder, Hollander and Angenot (1999) the researchers found similar results to Haisma *et al.* (2006). The results showed that physical capacity can be improved or maintained during the first year following discharge and that sports participation is associated with improvements in physical capacity. This further illustrates the importance of remaining physically active once discharged from inpatient rehabilitation.

In a review done by Hicks *et al.* (2011) physical capacity was defined as power output ( $PO_{peak}$ ) and aerobic capacity ( $VO_{2peak}$ ). The purpose of the review was to find evidence on the effects of exercise on the physical fitness levels of PWaSCI. The results showed that there is strong evidence that a combination of aerobic (arm ergometry) and resistance training performed two to three times per week at moderate intensity has the ability to improve physical capacity and muscular strength in PWaSCI. In a study conducted by De Groot, Hjeltnes, Heijboer, Stal and Birkeland (2003) the researchers measured physical capacity ( $VO_{2peak}$  and  $PO_{peak}$ ) at different training intensities in six recently injured spinal cord individuals. They showed that after a eight week arm interval training program  $VO_{2peak}$  and  $PO_{peak}$  significantly increased, especially in the high intensity training group vs the low intensity training group (150% vs 117% ( $VO_{2peak}$ ) and 154% vs 124% ( $PO_{peak}$ ) respectively). In another study conducted by Valent *et al.* (2009) participants with tetraplegia completed a eight week hand cycle interval training program (three sessions per week) and an increase of 20.2% was found in  $PO_{peak}$  and a 8.7% increase in  $VO_{2peak}$ .

Another form of training includes sports participation and as seen from the above, sports participation can help maintain and improve physical capacity one year post discharge. However, what frequency and intensity is required? In a study done by Dallmeijer, Hopman, Angenot and van der Woude (1997) the researchers investigated the effect of quad rugby training (1.5hours per week) on physical capacity in trained and untrained rugby players at pre-intervention, three and six months after quad rugby training. A stationary wheelchair ergometer was used to test  $VO_{2peak}$  and  $PO_{peak}$ . No measurable training effects were observed in physical capacity and the researchers therefore suggest that a higher training frequency and or intensity may be required to significant increases in physical capacity. There was, however, a significant rise in maximal isometric strength in the untrained group after three and six months of training. In another study conducted by Dallmeijer *et al.* (1996)



in persons with tetraplegia, the researchers found very low initial physical capacity levels (approximately 7.5ml/kg/min  $VO_{2peak}$  and 0.18 watt/kg  $PO_{peak}$ ), however after their intervention which included sports participation, physical capacity was improved. Sport activity proved to be the most important determinant for  $PO_{peak}$  and  $VO_{2peak}$ . In the results physical capacity improvements was explained by sport activity, lesion level and completeness of the lesion and there was a 70% increase in  $PO_{max}$  and 66% increase in  $VO_{2peak}$ .

In a study done by Kilkens, Dallmeijer, van Nene, Post and van der Woude (2005) the researchers proved that to function independently, manual wheelchair users require a variety of wheelchair skills and that physical capacity is related to the performance of wheelchair skills and wheelchair related ADL in PWaSCI. The results showed that upper extremity muscle force and  $PO_{peak}$  were important parameters in order to perform wheelchair skills. Thus learning wheelchair skills and improving physical capacity should be important goals during inpatient rehabilitation of PWaSCI (Kilkens *et al.*, 2005).

Janssen and his colleagues developed normative values for physical capacity in PWaSCI and the results are summarised in table 11 below.

**Table 11: Physical capacity norms for men with tetraplegia (TP), paraplegia (PP) (Janssen *et al.*, 2002) and able-bodied men (AB) (Heyward, 2010)**

Variable		Classification				
		Poor	Fair	Average	Good	Excellent
$VO_{2peak}$ (mL.kg <sup>-1</sup> .min <sup>-1</sup> )	TP	<7.60	7.61-10.00	10.01-13.39	13.40-16.94	>16.94
	PP	<16.50	16.51-22.70	22.71-29.20	29.21-34.35	>34.35
	AB	<41	42-45	46-50	51-55	>56
$PO_{max}$ (W)	TP	<11.6	11.6-20.0	20.1-26.8	26.8-37.5	>37.5
	PP	<52.7	52.8-70.4	70.5-82.1	82.2-97.8	>97.8
	AB	/	/	/	/	/

A reduced physical capacity has adverse effects on PWaSCI, however, changes in muscle morphology also occur soon after sustaining a SCI and the muscle tissue innervated below the lesion undergo a significant decrease in mass and shift in fibre phenotype (Kelley *et al.*, 2006), which also affects ADL and QOL. This is further discussed in section 2.5.3 below.

### 2.5.3. Muscle Strength

Changes in skeletal muscle structure and function are some of the earliest changes that can be observed following a SCI. This includes the loss of muscle mass (cross sectional area (CSA)) or muscle atrophy and can be seen from as early as one month post injury (Jacobs and Nash, 2004). After a complete SCI the muscle CSA can be 45-80% of that of their age-sex matched able bodied controls and can be seen as early as six weeks post injury (Pelletier, 2013). After an incomplete injury an approximate 24-31% loss in CSA is evident. The loss of muscle mass stabilizes approximately 11 months post injury (Pelletier, 2013). According to Pelletier (2013) and Biering-Sørensen, Kristensen, Kjaer and Biering-Sørensen (2009) changes can also be observed in the muscle fiber composition which changes from slow twitch fibers towards fast fatigueable fibre type (Type IIa/IIx). Muscle contractile properties are also affected, which in turn affects fatigue resistance, physical capacity and functional independence (Pelletier, 2013).

Most studies and exercise recommendations suggest that people in general should do strength training twice a week with one to three sets of eight to 12 repetitions per exercise for all the major muscle groups. Jacobs and Nash (2004) recommended three sets of eight to 12 repetitions per exercise for two sessions per week using the following equipment, free weights, machine weights and elastic tubes or bands. Regardless of the frequency and intensity of strength training, not many studies have been conducted in PWaSCI using strength training. Most research involves cardiovascular exercise, with less on the effects of weight training and functional electrical stimulation (FES) on physical capacity.

Hicks, Martin, Ditor, Latimer, Craven, Bugaresti and McCartney (2003) did, however, find that a resistance program followed twice a week was sufficient in improving strength in men and women with a SCI by 19-34% and that twice a week was easier to manage than three times per week. Jacobs and Nash (2004) found significant increases in strength (11.9-30%) in the shoulder muscles following a 12 week circuit training program followed three times per week.

Another type of exercise that can be used to obtain muscle hypertrophy is functional electrical stimulation (FES) (Devillard *et al.*, 2007). Bélanger, Stein, Wheeler, Gordon and Leduc (2000) found after applying FES to paralysed muscles for 24 weeks that there was a clear increase in muscle strength. The results also showed a faster increase in strength on the side that additional stimulus was applied. However, Hicks *et al.* (2011) stated that FES is traditionally used to activate muscles that can no longer be activated voluntarily in SCI individuals. The authors also mention that although FES assisted training enhances strength

in paralyzed muscles, the heterogeneity in FES training modes (cycling, walking and resistance training) make it difficult to determine the intensity of training in order to see improvements and secondly, FES is not tolerated equally by all individuals. Thus, it may not be appropriate for everyone. It is also a more costly form of exercise and may not be appropriate for community based PA programs essentially run by volunteers. FES can also only be applied to paralysed muscles, since its purpose is to restore and achieve function (Martin, Sadowsky, Obst, Meyer and McDonald, 2012) by stimulating the nerves that supply the specific muscle.

Weight training is therefore an activity that health care professionals can employ to increase muscular strength in PWaSCI (Jacobs and Nash, 2004) and help attenuate the effects of the injury. Improvements in muscle strength can enhance an individual's ability to perform ADL, such as transferring and wheeling and the increased muscle mass can also lead to metabolic benefits (Hicks *et al.*, 2011) such as an increased metabolism which in turn can contribute to weight loss.

As seen from the above sections (2.5.2 and 2.5.3), there is great variability in the modes and the intensity and frequency of training in PWaSCI, however, most authors agree that reconditioning after such an injury is possible and has a direct impact on function, QOL and completing ADL (Devillard *et al.*, 2007). To the researcher's knowledge no previous study has indicated that PA has any negative effects in PWaSCI. The only uncertainty is which form of exercise is most effective and due to the lack of evidence based research, no final conclusions can be made with regards to the more superior mode.

#### 2.5.4. **Balance and Flexibility (Range of Motion) Training**

For PWaSCI the ability to move freely to and from places is sometimes taken for granted and therefore maintaining flexibility is especially important as it assists with avoiding pressure sores, pain and injury (CORE, 2011). This collectively helps to avoid joint contractures and assists with maintaining joint integrity (NCHPAD, 2016). Muscle tightness also leads to shortened and weak muscles as a result of sitting for extended periods without stretching. Muscle tightness tends to develop in PWaSCI in the shoulder, chest, wrist and hip. Muscle spasticity also plays a role in muscle tightness and should therefore be addressed. Range of motion or flexibility exercises are performed to the joints capacity and help to ensure circulation to the joint and muscles. Range of motion or flexibility exercises are best carried out on a hard firm surface such as a plinth and by healthcare professionals (NCHPAD, 2016).

Another approach to flexibility training was investigated by Fagnani, Giombini, Di Cesara, Pigozzi and Di Salvo (2006). The researchers tested an eight week whole body vibration training program in elite female athletes to determine whether it can improve muscle performance and flexibility. The results showed that whole body vibration is a suitable training method to improve muscle activation and flexibility, which is important for the prevention of muscle-tendon injuries.

Independence in PWaSCI is an ultimate goal, and one key functional deficit that hinders this goal is poor balance (Kizony, Raz, Katz, Weingarden and Weiss, 2005). PWaSCI lack normal postural synergies and sensory integration to help regulate posture and therefore have to develop compensatory strategies to maintain balance. Poor balance can affect functional activities especially if one or both hands are required to complete a task or activity. Balance training can therefore improve functional abilities of PWaSCI and promotes independent living within community. Conventional therapy focuses on muscle strengthening and improving balance reactions. A new and emerging rehabilitation tool that was used in the research done by Kizony *et al.* (2005) included Virtual Reality (VR) – based technology. VR is able to produce simulated environments that users interact with, move, manipulate and perform actions in. The participant feels that they are in a certain environment and receive immediate feedback regarding their performance. In the study done by Kizony *et al.* (2005) the positive responses to exercise and expressions of interest in the system, suggests that it can be used as a modality to increase motivation for therapy as well. The participants also elicited high levels of presence, which helped the participants focus on a specific therapeutic task and not real world events during treatment sessions. The participants also experienced discomfort during the sessions that were comparable to conventional therapy, which possibly provides evidence that physiological responses (especially perceived effort exerted) also occur and could be similar to that achieved during conventional tasks (Kizony *et al.*, 2005). This ultimately improved the participant's physical capacity and well being as well (Kizony *et al.*, 2005). Lastly the results from the study also showed that there was a correlation between static balance ability and performance within the VR. The SCI group performed better than the nondisabled control group.

Another aspect of training that assists with independence is standing and sitting balance. PWaSCI can greatly benefit from balance and proprioception exercises as it helps to strengthen the supporting muscles and reinforces the neural component (CORE, 2011). Balance training also helps to increase function, reduces reaction times, which prevents injury and increases positional awareness (CORE, 2011).

Balance exercises should be performed by qualified personnel and with appropriate spotting techniques, especially standing balance. Standing balance can be trained between parallel bars or with a standing frame. Standing balance assists with strengthening of the muscles of the lower limbs, helps to prevent muscle atrophy, assists in maintaining joint integrity and promotes circulation (NCHPAD, 2016). Additional benefits include a reduction in spasticity and the promotion of a general sense of well being. A Swiss Ball can be used to train balance in the seated position as well as sitting unsupported. These types of balance exercises also help to establish an effective base of support and enable PWaSCI to complete tasks such as pressure relief, transfers with greater ease and ultimately independence (NCHPAD, 2016).

Other forms of balance training that have been researched include game based exercises and using locomotor training. In a study conducted by Betker, Desai, Nett, Kapadia and Szturm (2007) the researchers sought to improve balance from the short sitting position using game based training. The researchers found that dynamic short sitting balance can be improved using game based training as well as practice volume and attention span. Locomotor training can also be used to improve balance in patients with an incomplete SCI. In the study conducted by Harkema, Schmidt-Read, Lorenz, Edgerton and Behrman (2012) the researchers found that there was significant improvements in balance and walking measures in the patients from enrolment to their final evaluation before discharge.

#### **2.5.5. Alternative Therapies that can Improve Functional Ability in PWaSCI**

As mentioned previously one of the main goals in SCI rehabilitation is to restore or reduce the impact of the injury (Benson, Hart, Tussler and van Middendorp, 2016). In the past traditional therapies have been the main focus and included mainly Physiotherapy and Occupational therapy. More recently and especially in patients who have independent ambulation as high priority, the focus has shifted to more advanced assistive technologies that focus on locomotor training (Benson, Hart, Tussler and van Middendorp, 2016). One such therapy includes body weight-supported treadmill training with robotic assistance. Body weight-supported treadmill training has the potential to improve ambulatory capacity in PWaSCI. However, the effect of such training on independent ambulation has not been established (Benson, Hart, Tussler and van Middendorp, 2016). Body weight-supported treadmill walking is also limited to specialised rehabilitation centres. Another form of training includes, the exoskeleton and has demonstrated to aid ambulation in people with acute and chronic SCI (Benson, Hart, Tussler and van Middendorp, 2016). The exoskeleton is a wearable brace support suit that has motors at the hip and knee joints. It has rechargeable

batteries and a computer based control system and allows PWaSCI to walk independently in their community. Thus promoting increased participation and ultimately QOL in PWaSCI (Benson, Hart, Tussler and van Middendorp, 2016).

According to ReWalk (2016), over-ground powered exoskeletons have the potential to provide many physical benefits associated with upright mobility. Not only does an exoskeleton provide PWaSCI carry out functions such walking, standing, sitting and ascending or descending stairs, but in the study significant increases in ankle dorsi-flexion ( $1.7^{\circ}$  to  $6.9^{\circ}$ ), and in mean hip extension ( $8.2^{\circ}$  to  $14.1^{\circ}$ ) was also found after five days of training. No significant differences were observed in shoulder extension and internal and external rotation (ReWalk, 2016).

According to Aach, Meindl, Geßmann, Schildhauer, Citak and Cruciger (2015) training with the neurologically controlled exoskeleton HAL® can lead functional improvements (walking ability) in PWaSCI who have residual muscle function. Aach *et al.* (2015) also investigated whether there were any effects on bone density, bladder function and perfusion. The results showed that it was conceivable, but they could not adequately support their findings. Other studies also showed positive effects on spasticity and neuropathic pain. However, these results were only found in small clinical trials (Aach *et al.*, 2015). Although, exoskeletons are not an established rehabilitation tool, the systems will play a more significant role in PWaSCI in the future (Aach *et al.*, 2015).

## 2.6. The Great Divide

PA promotes physical health and psychosocial well being (Conchar, Bantjes, Swartz and Derman, 2014). PWD engage in PA for different reasons. For some it facilitates physical competence, enhances bodily appearances and independence and helps to keep the potentially harmful side effects of disability in “check” (Crawford and Stodolska, 2008). Apart from the physical benefits, sport participation is also associated with psychological benefits and allows an individual to regain identity and manage the stigma associated with a disabled body. It also helps to set goals and develop a sense of competence (Crawford and Stodolska, 2008). Sport also helps to integrate people with a disability into family and community activities. Hence it is essential to promote PA amongst marginalized groups such as PWaSCI.

According to the World Health Organization (WHO) and World Bank (2011) PWD have a poor health status, especially in developing countries and countries with a resource scarce environment. There are a number of reasons why PWD have a poor health status and this is

mainly attributed to the barriers they face. According to Washburn *et al.* (2002:1) lack of PA “may be associated with the gap between the individual’s needs, interests, and functional level and the barriers that are often present in their environment.” Moran, Taliaferro and Pate (2014) also stated that community based PA programs for PWD have barriers that are also unique to their program and the population they serve. Another aspect that should be considered according to Stephens, Neil and Smith (2012) is that PWaSCI acquired their disability and hence face different barriers to able bodied persons and other people with a congenital disability. According to Levins, Redenbach and Dyck (2004) persons with an acquired disability have a significant change in their social position, which is created by a lack of identity and loss of able identity.

In the field of psychology much work has been done in order to understand the factors that affect PA, however, the work has mainly focussed on able-bodied individuals and has been conducted in the developed world (Conchar *et al.*, 2014). Most research on what prevents (barriers) and facilitates PWD from being PA have been conducted in developed countries, however, according to Crawford and Stodolska (2008) 80% of the world’s population live in developing countries. Within developing countries PWD face additional obstacles, which may include the presence of civil war, environmental disasters, limited access to education, employment and health care (Crawford and Stodolska, 2008). According to the Rimmer (2008) many health disparities faced by PWD are not necessarily directly associated with the disability itself, but may directly or indirectly be due to the lack of good health promotion practices. In order to improve the health outcomes of PWD it is essential to understand the barriers and facilitators they face (Mlenzana, Frantz, Rhoda and Eide, 2013). In the field of disability, researchers have evaluated the perceived barriers that prevent participation or inclusion in adults with disabilities, but few studies were conducted specifically in individuals with a SCI.

Although regular PA has the potential to reduce the effects of inactivity on health and function associated with the disability, the barriers preventing people from partaking in PA must first be addressed. Health and fitness professionals have the potential to impact a large sector of the population that is underserved in terms of health and wellness. As people age there are greater physical demands on the body in terms of getting around the home and community. Hence tasks that were completed at a younger age becomes more difficult in later years, for example, carrying packages, transferring from a wheelchair to a bed, commode, pushing a wheelchair up a ramp/slope/over a curb. Each of these require a certain level of physical fitness whether its cardiorespiratory endurance, strength, flexibility or balance (Rimmer, 2008).

### 2.6.1. **Facilitators and Barriers to Physical Activity**

According to Spence and Lee (2003) physical inactivity is a major concern among industrialized nations and interventions aimed at changing individual dispositions that increase PA generally results only in small changes in behaviour. These changes may also dissipate in weeks and the theories such as the social cognitive theory and theory of planned behaviour and models such as the transtheoretical model explain only 20-40% of variance in PA. McNeil, Kreuter and Subramanian (2006) stated that there are several psychosocial, cognitive and emotional factors that explain why some people are inactive and others active. These individual factors play a major role, however, social, economic, political and physical environments also play an important role in health outcomes and behaviours (McNeil, Kreuter and Subraman, 2006). According to McNeil, Kreuter and Subraman (2006) the social environment should also be taken into consideration in order to foster behaviour change, since it is the social environment that inherently shapes behaviour. The social environment includes the bounds of families, communities and neighbourhoods and this is where most activities take place.

Most research in this field has focussed on individual barriers. This is partly due to the fact that social and structural determinants are more difficult to address. However, according to McNeil, Kreuter and Subraman (2006) the social and physical environmental contexts are key modifiable determinants of PA. It is therefore important to consider these determinants, along with individual determinants in order to foster health and wellness through PA.

Below is a review of the facilitators and barriers faced by PWaSCI in participating in PA. The facilitators and barriers were divided into four main categories according to Theory of Planned Behaviour (TBP) and include, personal, social, environmental and program/policy determinants. The TBP and other theories are further discussed in section 2.8.

### 2.6.2. **Facilitators to Physical Activity**

A facilitator according to the Merriam Webster dictionary (2015a) is one that helps to bring about an outcome (as learning, productivity, or communication) by providing indirect or unobtrusive assistance, guidance, or supervision. People, whether able bodied or disabled, engage in sport for similar reasons such as enjoyment, motivation, health benefits and social aspects (Jaarsma *et al.*, 2014). Below are the reasons why PWD, and more specifically those with SCI, participate in PA and/ or exercise and sport (Table 12).



**Table 12: Facilitators to physical activity and exercise**

<b>Facilitators</b>	<b>Description/Supportive Research</b>	<b>Reference</b>
<b>Personal</b>	154 able bodied participants completed the Exercise Motivations Inventory 2 (EMI-2) and the Exercise Causality Orientations Scale (ECOS), which measures motivators and barriers to exercise. The results showed that general health, maintain fitness, to feel good, strength and endurance and to feel energized to be facilitators to exercise.	Louw, Van Biljon and Mugandani (2012)
	SCI individuals become involved in sport for fun, improving physical fitness and health, competition and for the development and maintenance of social contacts.	Wu and Williams (2001)
	Achieving independence and the prevention of secondary conditions, as well as the perceived health benefits associated with activity.	Kehn and Kroll (2009)
	People with a disability also participate in sport because of the connection between disability and incapacity and reduced functional ability. Participating in sport acts as a means to prove themselves.	Stephens, Neil and Smith (2012)
	In people who have an acquired disability pre-injury sports participation influences post injury participation and the focus should be on positive experiences gained prior to the injury. They also placed emphasis on establishing social contacts and that getting people involved and introduced to other people with a disability be done as soon as possible.	Jaarsma <i>et al.</i> (2014)
<b>Personal and Social</b>	Disability sport is a way of demonstrating competence and reducing the reliance on others. They also reported that SCI individuals who participated in sport had improved autonomy because of formal and incidental learning from others.	Page, O'Connor and Peterson (2001)
<b>Social</b>	Most wheelchair users who engaged in PA returned to their pre-injury level of social contacts. Thus role models also play an important role in future sports participation.	Pluym <i>et al.</i> (1997)

	<p>The social facilitators in the study included social support, private finances, improved physical appearance, role models and achieving independence. Previous studies have shown that other PWD who are physically active are good introductory agents.</p> <p>Role models were instrumental as the participants showed interest in becoming a role model themselves. Being able to share experiences and knowledge with others was a source of satisfaction. There remains a need in rehabilitation to develop structured systems that will help encourage individuals to become role models to others.</p>	<p>Stephens, Neil and Smith (2012)</p> <p>Wahman <i>et al.</i> (2006)</p>
<b>Environmental</b>	<p>Found the following benefits of exercise that in turn could potentially lead to exercise or lifestyle change. Family changing rooms, adaptive equipment, knowledge about exercise, positive influence from personal contacts, policy changes encouraging accessibility and education.</p>	<p>Malone <i>et al.</i> (2012)</p>
<b>Program / Policy</b>	<p>In this study the facilitators were; positive personal attitudes, individual tailored programs, and a facility that supports people with similar conditions and disabilities and an exercise program that considers individual motivators.</p>	<p>The Life Group (2011)</p>

People engage in PA for different reasons. For some, immediate engagement in PA is necessary to re-establish a positive self identity and for others, PA only becomes important later (Levins, Redenbach and Dyck, 2004). Individuals undergoing rehabilitation often view physical therapists as an “expert” and the treating therapists view as fact (Whiteneck *et al.*, 2011). Lowered expectations by the therapist “could lead to patients only striving for those goals that are envisioned for them” (Levins, Redenbach and Dyck, 2004:508). Thus Levins, Redenbach and Dyck (2004) suggested that increased knowledge about the factors contributing or deterring an individual from participating in PA should be identified. This will contribute to promoting a healthy lifestyle after discharge. There is therefore a lot of work that needs to be done in developing countries within the disabled population in order to identify the factors that influence participation in PA.

As seen from the above table, personal facilitators are the main reason why people exercise or participate in PA. However, society and the environment play a major role as to why people do not exercise and it is important to keep in mind when advising PWD about participating in PA. Providing PWD with the information that they may face potential barriers, might help them overcome these barriers or make it easier for them to overcome if they do encounter them (Jaarsma *et al.*, 2014).

### 2.6.3. Barriers to Physical Activity

A constraint, according to the Merriam Webster dictionary, is something that limits or restricts someone's actions or behavior (Merriam-Webster, 2015b). For the purpose of this research a barrier is anything that prevents or directly hinders participation levels (Stephens, Neil and Smith, 2012). In South Africa chronic disease and risk factor prevalence is high and PA participation is low (Lambert, Kolbe-Alexander, Steyn, Fourie and Temple, 2006). It is important therefore to understand why people do not partake in regular PA, in order to lower the burden of chronic diseases within South Africa. Within the able bodied population, frequent barriers that are mentioned include lack of time, lack of motivation and difficult access to facilities (Jaarsma *et al.*, 2014). In the study done by Louw, Van Biljon and Mugandani (2012) lack of time, other priorities, perception that daily routine provides a workout, lack of energy and health issues were amongst the most common barriers. Other barriers that were mentioned, included lack of an exercise partner, especially in younger individuals, and lack of knowledge, amongst the more senior groups. People with physical disabilities experience similar but also additional barriers and these barriers are summarised below, in table 13.

**Table 13: Barriers to physical activity and exercise**

<b>Barrier</b>	<b>Description/Supportive Research</b>	<b>Reference</b>
<b>Personal</b>	Multiple factors have been identified to influence PA levels in PWaSCI. There is an interwoven relationship between motivational triggers/constraints such as personal assistance or education about PA and socio-environmental resources/barriers such as accessibility.	Kehn and Kroll (2009)
	In this study mental problems such as a sad feeling and physical problems such as bladder problems prevented people from participating in PA.	van den Berg-Emons <i>et al.</i> (2008a)

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	<p>Barriers to PA included gaining access to appropriate wheelchairs, learning new skills involved in wheelchair sports and reduced self confidence.</p>	Tasiemski <i>et al.</i> (2004a)
	<p>Health limitations, lack of time or lack of money were barriers for PWD. Interestingly another barrier included difficulty in getting the appropriate sporting wheelchair, with access, coaching and travel not being identified as barriers to sport participation. A finding not reported in previous research is that preparation for sport may take longer for disabled than for able bodied athletes. It was reported that individuals with disabilities take longer to do tasks such as getting dressed and getting into a car along with frequently encountered parking difficulties.</p>	Stephens, Neil and Smith (2012)
<p><b>Personal and Social</b></p>	<p>Although the barriers mentioned above are similar to those faced by PWD in developed countries, they are exacerbated by the fact that they live in a developing country. Within developed countries lack of money is a major barrier and listed by most people, however, in developing countries the lack of money also causes athletes to show up to practice hungry in addition to not being able to provide for their families with basic necessities.</p>	Crawford and Stodolska (2008)
<p><b>Personal, Environmental and Program/ Policy</b></p>	<p>Perrin identified eight constraints and some include poverty, inaccessible transportation, lack of knowledge of leisure opportunities, and segregation of programs and activities.</p> <p>The authors stated that with appropriate support and information PWD can be successful in managing their own needs and therefore feel healthy. However evidence have shown that the health needs of people with a disability are not adequately met. This is due to lack of financial access and attitudinal barriers.</p>	Perrin (1992) cited in Crawford and Stodolska (2008) Shakespeare and Kleine (2013)
<p><b>Personal and Environmental</b></p>	<p>Henderson found that woman with disabilities also experienced some of the general constraints and include lack of time/money, ethic of care, safety,</p>	Henderson, 1995 (in Crawford and Stodolska, 2008)

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	<p>energy deficiency and lack of opportunities and choices.</p> <p>According to the World Health Survey PWD were twice as likely to find health care provider skills and equipment inadequate to meet their needs. They were also three times more likely to be denied access to health care and four times more likely to be treated badly by providers.</p> <p>Amongst African American woman Rimmer reported that lack of transportation, inability to pay for fitness membership, lack of knowledge about where to go or how to exercise and lack of understanding the importance of exercise in improving their condition.</p>	<p>Shakespeare and Kleine, 2013</p> <p>Rimmer <i>et al.</i> (2004)</p>
<b>Social</b>	Participants did not feel they received adequate information on sports and opportunities to engage in PA following discharge.	Stephens, Neil and Smith (2012)
<b>Social and Environmental</b>	In the study decreased employment opportunities, limited social support and family role functioning, limited access to recreational and leisure activities, and lack of accessible transport were found to be barriers.	Magasi <i>et al</i> (2008)
<b>Environmental</b>	Historically access to public places limited PWD from participating in social and recreational activities. In one study it was reported that wheelchair users were unable to utilise facilities due to bad weather/climate, no curb cuts or blocked curb cuts, limited strength or physical fitness, inaccessible doors and bathrooms, no parking, poor travel surfaces, obstructed travel, personal illness, no ramps or ramps too steep and lastly wheelchair problems.	Rimmer <i>et al.</i> (2004)
<b>Environmental, Program/ Policy, Personal and Social</b>	Most of the barriers are categorized as structural and include lack of funding, problems with facilities and transportation and lack of equipment. Other barriers included physical barriers that prevented PWD from entering the premises. These included heavy doors and heavy carpets that affected the mobility and	Crawford and Stodolska (2008)

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	<p>limited space in the changing areas as well as poor signage.</p> <p>Lack of transportation, lack of access to their community, fear about leaving home, cost of an exercise program, lack of experience amongst fitness centre staff, lack of privacy, fear of injury and public exposure. Most of the study participants also indicated that their physician did not recommend exercise. In persons with tetraplegia the exercises were too difficult and health concerns prevented them from participating in exercise.</p> <p>Consistent barriers to health promotion have included the cost of programs, lack of awareness of fitness facilities, lack of transportation, lack of knowledge and how or where to exercise.</p>	<p>Scelza <i>et al.</i> (2005)</p> <p>Malone <i>et al.</i> (2012)</p>
<b>Program/policy</b>	<p>In this study which was conducted in the U.K and other developed countries, agencies that provide recreational programs to PWD were investigated and they found that lack of funds to hire specialists and qualified staff, buying of adaptive equipment and lack of adaptive transport to be major barriers.</p>	<p>Crawford and Stodolska (2008)</p>
<b>Personal, Social, Environmental and Program / Policy</b>	<p>According to the authors there are also limited options for organised PA for PWD within the school setting as well as the community setting.</p> <p>The researchers developed and evaluated an exercise support system for persons with neurological disabilities and during their evaluation the following barriers were identified; practical and organizational factors (lack of suitable local gyms that are accessible and safe), lack of suitable equipment, transport (unavailable/inappropriate/costly), negative personal experiences and attitudes such as fear and embarrassment of exercising (especially in presence of fit and healthy individuals) and perceptions that fitness staff will lack knowledge about their condition.</p>	<p>Moran, Taliaferro and Pate (2014)</p> <p>The Life Group (2011)</p>

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The researchers found that lack of possibilities, lack of accessibility, energy levels, transportation, information access, qualification of supervision, and adjustment of facilities to be the main barriers. Jaarsma *et al.* (2014)

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From the above it is clear that PWaSCI face many challenges in being PA, whether residing in a developed or developing country. The major barriers that seem to affect PWD the most globally included lack of money, inaccessible and/or lack of transport, inaccessible buildings or lack of facilities and lack of staff and/or qualified staff to assist where needed. This once again stretches the point that appropriate community based PA programs are required that address these barriers and foster health and wellness amongst PWD.

According to Rimmer *et al.* (2004) not very much is known as to why the majority of PWD do not integrate PA into their lifestyles. Rimmer and his colleagues (2004) suggested that understanding these barriers could provide important information which is necessary to develop successful interventions. According to Rimmer

“The aim of a health promotion program for PWD are to reduce secondary conditions, to maintain functional independence, to provide an opportunity for leisure and enjoyment, and to enhance the overall quality of life by reducing environmental barriers to good health.” (Rimmer, 1999:495)

In order to achieve this more community based health programs must be put into place for PWD. This is of particular importance since research has shown that rehabilitation services have declined, which translates into shorter hospital stays which ultimately leads to post rehabilitation health decline and negative effects on the person’s health (Rimmer and Henley, 2013). Thus most patients are expected to continue their recovery elsewhere. Often these programs are without ancillary services, which are needed to achieve good progress (Rimmer, 1999).

As mentioned above PWD and more specifically for the purpose of this study PWaSCI face many barriers that prevent them from participating in PA programs. In order to remove the barriers faced by persons with a disability it is imperative to understand the type and nature of the barrier. Rimmer and Schiller developed a model/framework that systematically addressed barriers in the built environment, namely RAMP (Restoring Activity, Mobility and Participation) (Rimmer *et al.*, 2008). The RAMP model can be seen in Figure 1.

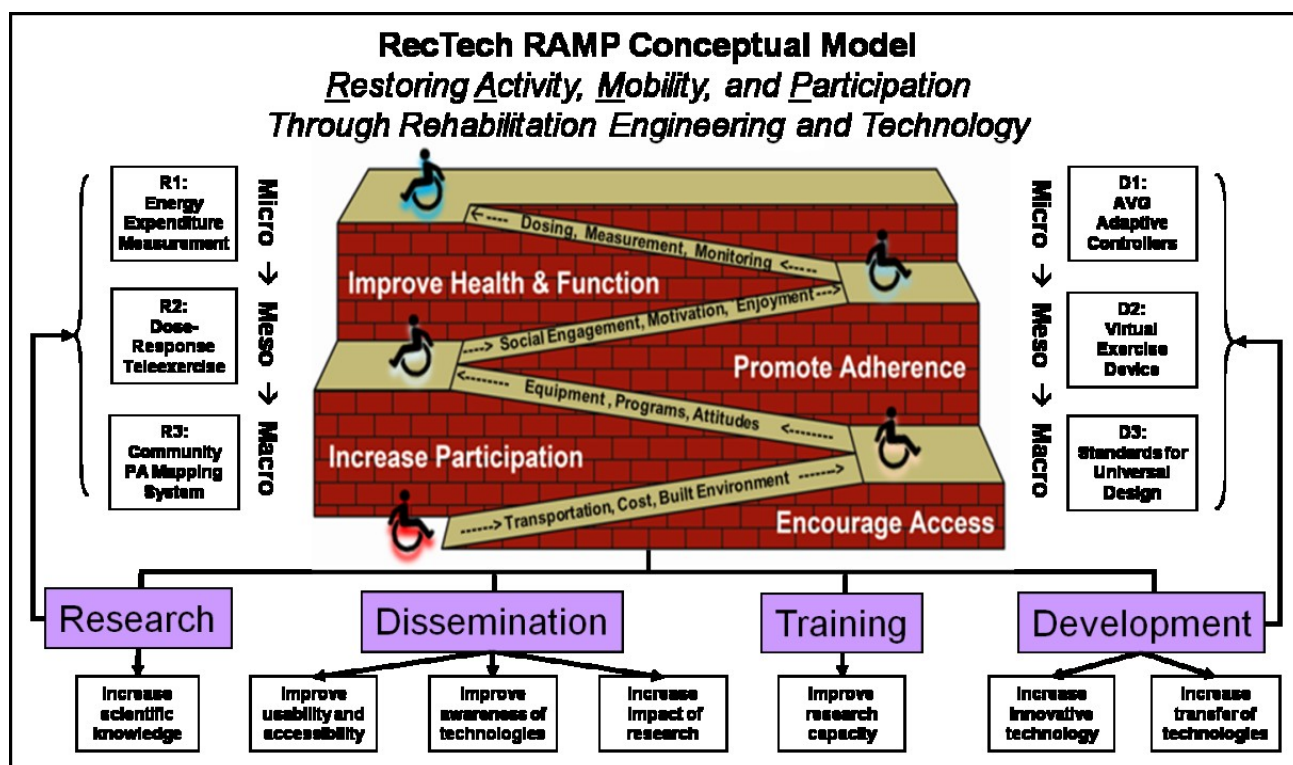


Figure 1: Rec Tech RAMP model (Rimmer *et al.*, 2008)

The model above consists of four essential components namely, access, participation, adherence and health and function. Each component builds upon the next, with the ultimate aim being to achieve optimal health and wellness amongst PWD. The program in this study will use the RAMP model as a guide to implement a sustainable PA programme amongst PWaSCI in South Africa.

## 2.7. Community Based Health and Wellness

Wellness according to Henderson and Armah (2010) is the collective importance of mind, body and spirit in maintaining health. According to the authors wellness can be divided into six major dimensions namely, physical, spiritual, social, emotional, intellectual and environmental (Henderson and Armah, 2010). The physical dimension is about exercise and healthy eating habits, the spiritual dimension about a positive perception of meaning and purpose in life, being open to different cultures and spending time doing meaningful activities. The social dimension looks at available support from family, friends and co-workers in times of need as well as being a valued support provider. The emotional dimension includes having a secure self-identity and positive sense of self-regard together with the ability to cope with or improve mood states. Intellectual wellness is defined as being internally energized by an optimal amount of intellectually stimulating activities and lastly



environmental wellness is the positive perception of the environment in which the person works or lives (Henderson and Armah, 2010).

According to Henderson and Armah (2010), community based wellness programs are initiatives that occur outside of primary care centres and secondly give the community an opportunity to proactively address, their own health and wellness concerns. According to Bush *et al.* (2002) a community can be defined as any existing or potential network of individuals, groups or organizations that share or have the potential to share common concerns, interests and goals (cited in Chau, 2007).

“Physical activity is a behaviour that is associated with individual, social and economic factors as well as the physical environments in which individuals live.”  
(Chau, 2007:4)

According to the authors there is a relationship between physical activity and community factors. Not only are there potential health benefits for individuals within the community but also for the community at large.

Paronen and Oja (1998:171) identified six key features that make up a community. The first is that a community is typified by membership, which means members have a sense of identity and belonging. The second aspect is that a community consists of common symbol systems, which includes language, religion and practices. Thirdly, community members share common norms and values and fourthly, there is a mutual influence, whereby people influence and are influenced by others. Second to last, a community is characterised by shared needs and commitment to meeting those needs and lastly, community members typically share an emotional connection in the form of common history, mutual support and similar experiences.

Community based wellness programs have the biggest impact specifically in areas where health care is limited and poverty is widespread (Henderson and Armah, 2010). Community based wellness programs make it possible for people to act on information they acquire, for example, that sixty minutes of exercise can improve a child's test scores. A community wellness program is a simple, cost effective way for municipalities to deliver preventative public health related services. Community based wellness programs are driven by the community itself and not the government. Community based wellness programs integrate all sectors of the community by design and therefore become embedded quickly and naturally.

Rimmer (2012:857) stated that “communities and neighbourhoods across the world lack receptivity in promoting physical activity environments that support the needs of PWD.” According to Rimmer (1999) and the Healthy PWD Act, 2010 health promotion for people with a disability consists of the following aspects: 1) the promotion of healthy lifestyles and a healthy environment, 2) the prevention of health complications and further disabling conditions, 3) the preparation of the person with a disability to understand and monitor his or her own health and health care needs and 4) the promotion of opportunities for participation in commonly held life activities. As mentioned above part of the problem is that facilities are not accessible, professionals that work in these facilities are not trained to work with PWD, lack of accessible equipment and a lack of adaptive programs (Rimmer and Henley, 2013). It is important that a continuity of recovery (linking rehabilitation and the return to home) be provided in order to facilitate community wellness (Rimmer and Henley, 2013). However, rehabilitation specialists have limited options as to where to refer their patients after the completion of inpatient rehabilitation. Hence, patients return home to a life with limited options, no employment, the reduced ability to complete ADL and less access to sport, recreation and fitness (Rimmer, 2012). As mentioned previously PWaSCI are at risk of developing secondary conditions and prevention strategies are necessary. Health promotion activities can have a positive impact on reducing the occurrence of these conditions and improving overall health and function in persons with a newly acquired disability. Healthcare professionals have the opportunity to capitalize on a person’s readiness to continue his or her recovery after rehabilitation. Patients often experience success during rehabilitation in terms of progress and may therefore be more motivated and interested in continuing his or her recovery when rehabilitation ends. Rehabilitation, thus serves as a medium to start an exercise program after rehabilitation (Rimmer, 2012). Community based facilities, however, also have their draw backs in that most are not tailored for PWD in terms professional service and access to equipment, programs and services. Therefore, it is important to establish community based programs that overcome these barriers.

According to the WHO (2008), health is one of the fundamental human rights and a robust and accessible health system is required to fulfill this right (cited in Grut, Mji, Braathen and Ingstad, 2012). People in poor or less developed countries have less access to health services and within these less developed countries the poor have even less access than citizens who are better off. PWD are considered more vulnerable in this regard especially in poor and rural areas. In general, PWD are among the most marginalized and vulnerable groups of any population and often get excluded from health services (Grut *et al.*, 2012). As mentioned above PWD face many barriers to health and wellness and one factor include unavailability and accessibility of such health services. Within the African context, South

Africa has a fairly well developed health system and health policies, were among the first policies paid attention to by the ANC-led democratic government in 1994. Although South Africa may seem wealthy compared to other African nations, poverty is still a major problem and affects a large majority of the population and hence access to health care is still out of reach for many. Due to wide spread poverty most people are dependent on social grants such as a disability grant and child support grants.

According to Statistics South Africa (cited in Grut, Mji, Braathen and Ingstad, 2012) 1.1 million people out of 50 million people received disability grants in 2007. Poor people's choices are affected by many factors and together with barriers, it creates difficult circumstances that may prevent people from accessing health services. Grut, Mji, Braathen and Ingstad (2012) mentions that the link between poverty and disability cannot be ignored and future health services should focus on involving skilled and specialized medical and health professionals in outreach and home based services. Community based health programs should acknowledge and take into consideration that a person's life is influenced by a variety of factors and include social, cultural and political factors. Hence improving the skills of the community health workers in basic health and rehabilitation could take some of the load off parents and families taking care of PWD (Grut, Mji, Braathen and Ingstad, 2012).

Hence a new approach that will provide people with a neurologic disability with an opportunity to continue their recovery in a community based health and wellness setting is required (Rimmer and Henley, 2013). According to Rimmer and Henley (2013), opportunities to continue the individual's recovery in a community facility have the potential to increase health, social integration and community participation. In a review done by Cleland, Tully, Kee and Cupples (2012), the authors stated that multilevel interventions are needed to increase PA levels, especially in "hard to reach" communities. Interventions should also take into consideration the social, cultural, educational and economic situations of the individuals. Cleland, Tully, Kee and Cupples (2012), also stated that group-based interventions targeting adults are most effective and the best hope of reducing health inequalities is with interventions implemented at community level.

Within the Western Province of South Africa the following conditions are mainly seen and in need of rehabilitative services; arthritis, SCI, head injury, neuromuscular disorders, stroke, fractures and amputations (Mlenzana *et al.*, 2013). Investing in health and rehabilitation services contributes to equality of opportunities and ensuring good QOL for PWD. It also promotes social participation and makes a valuable contribution to society. According to the UN Convention on the rights of PWD, the rights of PWD to play an active role in society is

key and that access to rehabilitation services play a role in achieving this goal (Mlenzana *et al.*, 2013).

## **2.8. Improving Physical Activity Behaviour after Rehabilitation within South Africa**

A physically active lifestyle, however, can help to reduce the effects of these problems, hence reducing the disability. Although most people know about the benefits of PA, getting started and maintaining that behaviour is difficult. Although patients may be very active during the rehabilitation process, this PA level is easily lost after being discharged from the hospital (van der Ploeg and van Mechelen, 2004). This is mainly due to the individual adjusting to the new lifestyle, as well the fact that there are very few facilities available for PWD to continue their active lifestyle. According to van der Ploeg, van der Beek, van der Woude and van Mechelen (2004), the sudden lack of planned and structured activities after rehabilitation is not replaced by self initiated activities.

This warrants the development of effective PA interventions that allows for patients to participate in regular PA. In order to implement a successful PA program, understanding the determinants that affect PA behaviour should be understood (van der Ploeg, Streppel, van der Beek *et al.*, 2008). According to van der Ploeg, Streppel, van der Beek *et al.* (2008) a person's intention and actual PA level is thought to be determined by personal and environmental factors. According to the Physical Activity for People with a Disability Model (PAD model) attitude, self efficacy, an individual's health condition, personal and environmental barriers and facilitators, and social factors influence this behaviour. Knowledge about these determinants can be helpful in designing PA programs (van der Ploeg, Streppel, van der Beek *et al.*, 2008).

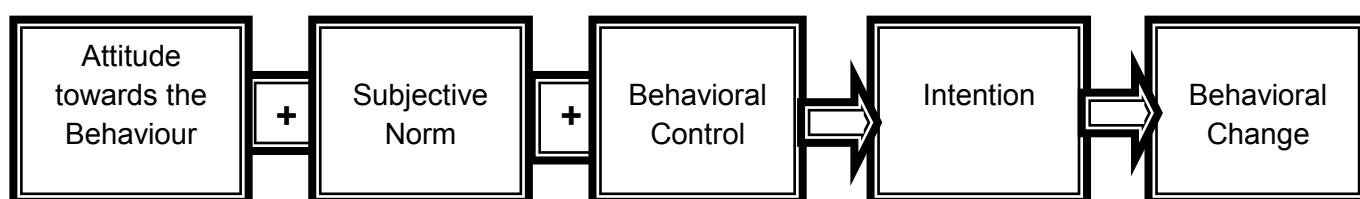
Although the determinants have been identified, behavioural theories have also been employed to help understand and improve PA behaviour. However, according to Baranowski, Anderson and Carmack (1998) interventions to promote PA using behavioural theories account for 30% or less of the variability in PA behaviours. In most cases the interventions worked when participants were motivated enough to volunteer to participate (Baranowski, Anderson and Carmack, 1998). Within the PA context and health behaviour four main theories have been utilized namely, the Social Cognitive Theory (SCT), the Theory of Planned Behaviour (TPB) (Perrier, Shirazipour and Latimer-Cheung, 2014), the Self Determination Theory (SDT) and the Transtheoretical Model (TTM) (Buchan, Ollis, Thomas and Baker, 2012) (Table 14). Buchan, Ollis, Thomas and Baker (2012) agreed that the use

of these theories has enhanced the understanding of PA behaviour in terms of the psychological influences and processes involved. The authors also agreed that even though these theories have enhanced the understanding, little has been done to eradicate health problems. These theories are also relatively successful in predicting intentions, however, they do not account for the variance in behaviour (Perrier, Shirazipour and Latimer-Cheung, 2014).

**Table 14: Theories to improve physical activity behaviour**

<b>Theory/Model</b>	<b>Description</b>	<b>Reference</b>
<b>Theory of Planned Behaviour</b>	The theory is a cognitive, behavioural approach to understanding and predicting behaviour. According to the theory, the best predictor is intention to perform the behaviour. Intentions are influenced by behavioural beliefs, positive and negative attitudes towards the behaviour, normative beliefs, and individual perceptions of what significant other believe they need to do, perceived behavioural control (self efficacy) and whether he/she has control over the performance of the behaviour.	Gulley and Boggs (2014)
<b>Transtheoretical model</b>	This theory is based on stages and posits that health behavior change involves six stages. These stages include, precontemplation, contemplation, preparation, action, maintenance and termination	Prochaska and Velicer (1997)
<b>Social cognitive theory (Bandura, 1986)</b>	The theory illustrates the interactive relationship that exists between individuals and environments. Behaviour must also be addressed on multiple levels of influence.	McNeil et al.(2006)
<b>Self Determination</b>	The theory is based on intrinsic and extrinsically motivated factors that affect PA. Intrinsic motivation refers to engagement in an activity because of the inherent pleasures and satisfaction it provides. Extrinsic motivation is characterised by a separable outcome such as a tangible reward, an avoidance of punishment or the attainment of recognition etc.	Ryan and Patrick (2009)

According to Buchan *et al.* (2012) changing behaviour is not as straight forward and is a complex and multifaceted phenomenon with many levels of influence. Thus, in order to achieve enduring behavioural changes multi level interventions are needed. Such interventions should focus on individuals, social environments, physical environments and policies (Buchan *et al.*, 2012). This is concurrent with the TPB, which was used to identify, group and eliminate the barriers faced by PWaSCI in participating in PA. The TBP is one of the most widely applied models of the cognitive determinants of behaviour (Rivis and Sheeran, 2003) and explains why people take up PA and or exercise and continue this behaviour (Bozionelos and Bennett, 1999). In figure 2 the TBP process is summarised.



**Figure 2: Theory of Planned Behaviour Process**

According to Bozionelos and Bennett (1999) behavioural intentions are derived from two parallel cognitive processes and they include consideration of the individual's own attitude towards the behaviour and consideration of the relevant behavioural norms. Both processes comprise of two aspects. Attitude towards the behaviour comprise of beliefs about the behaviour and "valences" attached to those beliefs. Behavioural norms comprise of subjective norms (social influence) and the motivation to comply with other people's views (Bozionelos and Bennett, 1999; Rivis and Sheeran, 2003). Behavioural control is the third aspect and takes into account past experience and external factors (e.g. obstacles or resources), that may influence the performance of the behaviour (Bozionelos and Bennett, 1999). Altogether the more positive the person's attitude and subjective norms and the greater the perceived behavioural control regarding a specific behaviour, the stronger the person's intend to perform the behaviour becomes (Rivis and Sheeran, 2003).

Another aspect to take into consideration to foster behavioural change is the community within which PA takes place. When working in different communities it is important that the needs and concerns of each community also be taken into consideration when planning community PA initiatives (Chau, 2007:6).

“People are more motivated to engage in physical activity in a friendly environment, when there are opportunities to socialise, and when the activity is enjoyable and personally rewarding”.

This highlights once again the importance of the social environment and supports the TBP in that a socially connected environment will lead to PA opportunities through social interactions (Chau, 2007) and possibly to permanent PA behavioural change, that is required in order to achieve health and wellness.

## **2.9. Summary**

This chapter has provided a review of the literature that is relevant to the study. Most of the research reported within the chapter has been from other countries, since there is limited research done in the field of PA and SCI within South Africa. Most of the research has also been conducted in developed countries such as the United States, Australia and Europe. Thus the information provided might not be applicable to the South African context. Nonetheless the literature does provide important information regarding the many challenges or obstacles that PWaSCI face in attaining health and wellness through PA, whether it is personal (e.g. secondary health conditions), social (e.g. society and their perceptions of PWD), environmental (e.g. physical obstacles) or policy (e.g. lack of PA programs) barriers. The literature also helps us to understand the difference that exists between the developed world and the developing world and the journey to integrate PWD into communities.

## CHAPTER 3

### METHODOLOGY

#### 3.1. Introduction

The methodology is divided into two main sections. Firstly the research questionnaire, which was used to determine the barriers and the facilitators faced by PWaSCI in attaining health and wellness through PA. Secondly, the intervention, which was further divided into three main parts namely, identifying and securing the training environment within different communities, recruitment and training of the volunteers to run the PA sessions and lastly implementing the exercise program within the different training environments.

#### 3.2. Research Approach

The explorative nature of this study required that both objective and subjective measurements be taken. Therefore a mixed method approach was chosen since it incorporates both quantitative and qualitative methodologies (Creswell, 2003). This method was chosen as it gives the researcher more information and insight into the aspects that affect health and wellness in PWaSCI.

The subjective measurements refer to the research questionnaire and the modified Reintegration to Normal Living Index (mRNLI) questionnaire that each individual completed. These questionnaires were completed by the participants at four time points (pre, two months post, four months post and six months post-intervention). The objective measurements refer to the physical testing that was completed at three time points (pre-intervention, two and four months post-intervention).

#### 3.3. Research Setting

The research took place in three different areas within the Western Cape, namely Strand, Macassar and Mitchells Plain in Khayelitsha. The Mitchells Plain setting was used as the formal rehabilitation setting, while the Strand and Macassar groups were combined for the community based setting. These areas were identified by the researcher as they were easily accessible and already established contacts were operating in these specific areas. This was necessary as there is a lack of infrastructure in South Africa in locating PWaSCI and recruiting them for research purposes.



### 3.3.1. Study Population

The study population for this study was PWaSCI living in the Western Cape, more specifically in the areas of Strand, Macassar and Khayelitsha.

### 3.3.2. Participant Selection

The study participants were recruited from two independent organizations within the Western Cape namely the Western Cape Rehabilitation Centre (WCRC) and Senecio, a Non Profit Organization (NPO). The participants for phase II of the research were recruited after the completion of the research questionnaire (APPENDIX A) through purposeful sampling and having met the inclusion criteria stipulated below.

#### **Inclusion Criteria**

Participants were included in the study if they met the following criteria:

1. Aged between 18-65 years
2. Have completed the PAR Q and YOU health questionnaire (APPENDIX C) and according to the questionnaire had no contraindications to exercise.
3. Have:
  - a. A SCI below and including C4 neurological level of injury (ASIA Classification Scale A-D)
  - b. Paraplegia
  - c. Quadriplegia
4. Speak English, Afrikaans or Xhosa
5. According to American College of Sports Medicine (ACSM, 2013) have only one risk factor for atherosclerotic disease (cardiovascular, pulmonary or metabolic disease).
6. According to ACSM (2010) guidelines have more than 1 risk factor for atherosclerotic disease, but are cleared by a physician to participate.
7. Able to manually propel a wheelchair during exercise sessions.

#### **Exclusion Criteria**

Participants were excluded from the study if they had any knowledge of the following criteria:

1. Cardiovascular contraindications to exercise (ACSM, 2013).
  - a. A recent significant change in the resting ECG suggesting significant ischemia, recent myocardial infarction (within 2 days) or other acute cardiac event
  - b. Unstable angina
  - c. Uncontrolled cardiac dysrhythmias causing symptoms or hemodynamic compromise

- d. Symptomatic severe aortic stenosis
  - e. Uncontrolled symptomatic heart failure
  - f. Acute pulmonary embolus or pulmonary infarction
  - g. Acute myocarditis or pericarditis
  - h. Suspected or known dissecting aneurysm
  - i. Acute systematic infection, accompanied by fever, body aches, or swollen lymph glands
2. Additional co-morbidities that will affect response to exercise, such as diabetes.
  3. A resting systolic BP >180mmHg and a resting diastolic BP >90mmHg
  4. Compromising complaints of the musculoskeletal system e.g. current shoulder injury.
  5. Have pressure sores and/or a bladder infection.
  6. Missed four consecutive exercise sessions or more than six sporadic sessions.

A total of 57 participants completed the initial research questionnaire and of these 20 participants volunteered (sample of convenience) to partake in the study. The sample was divided into two experimental groups (n =10 each) based on their location. During the intervention four participants withdrew from the study and their reasons for withdrawing from the study are discussed in section 5.2.

### **3.4. Statistical Analysis**

#### **3.4.1. Phase I: Research Questionnaire**

The data for Phase I was analyzed using Excel 2007. Descriptive statistics regarding the socio-demographic and injury profile data were reported as frequencies and percentages. The data on the barriers and facilitators were also reported as frequencies and percentages of the total number of barriers or facilitators that were selected by the participants.

#### **3.4.2. Phase II: The Intervention**

Data for Phase II were analyzed using SPSS (IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp). Firstly the changes of the physical abilities of the participants over time and the comparison between the two groups were evaluated using Generalised Estimating Equations (GEE). GEE enables correction for dependency of observations within individuals over time, by choosing a 'working' correlation structure. An independent correlation matrix was chosen which implies that the within-participant correlation between the different measurements was considered zero.

From the questionnaire data, barrier counts were analysed using mixed model repeated measures ANOVA with group and time as fixed effects and the participants as random

effect. Comparison of categorical variables was done using cross tabulation with the Chi-square test (or Fisher exact test where appropriate). The barriers and facilitators that were identified by the participants were also reported as frequencies and percentages. The percentage reduction over time was also calculated within the groups. Both the frequencies, percentages and percentage reduction were calculated using Excel 2007.

### **3.5. Ethical Aspects**

#### **3.5.1. Ethical Considerations**

The protocol was submitted to and approved by the Sport Science Department's Ethics Committee and the Ethics Committee for Human research (Humanoria) at Stellenbosch University (HS1028/2014).

##### **3.5.1.1. Phase I: Research Questionnaire**

Agents were identified to help distribute the research questionnaire. All the agents were formally invited by the principle investigator and promoter. All agents gave a written acceptance letter to participate in the study (APPENDIX M).

All the participants who volunteered to complete the research questionnaire were required to complete an informed consent first. Upon completion of the questionnaire, participants had the option to partake in the intervention. All information on the questionnaire was kept confidential to protect the participant's identity, by assigning a number to each of the participants. All completed hard copies of the questionnaires were kept in a box in a secured area during data input and upon completion of the study the information was secured in a safe at the Sport Science Department. All hard copies were also scanned and saved in a password protected file. Access to these questionnaires was only granted to the principle investigator and promoters.

##### **3.5.1.2. Phase II: The Intervention**

Participants who completed the research questionnaire had to volunteer to partake in the intervention. Once the participant signed the informed consent to partake in the intervention they underwent a screening process and they had to meet the inclusion criteria. Once they were cleared to partake in the intervention they were informed that they may withdraw from the study at any time with no consequences. Before the study commenced participants were informed about the procedures and tests they would undergo. All information about each subject remained confidential (by assigning a number to each participant) and access to data was only granted to the principal investigator and promoter. The data gathered during

the initial testing and exercise sessions were stored on a password protected computer. The anonymity and confidentiality of each participant was respected by omitting their names from the data analysis.

Identifying the most suitable training facilities indirectly affected the participants in terms of safety and accessibility. If venues were not suitable for participants, possible injury could result as consequence. Extra precaution was taken in order to avoid injury by the training of volunteers and making sure the venues that were used were safe.

The recruitment and training of volunteers was very important in determining program success. Selecting volunteers that were not suited for the program could lead to potential injury of the participants should the volunteer be careless or irresponsible. Hence training of the volunteers was provided and continued communication and training was offered where needed. If volunteers also did not show up for training sessions it affected the program success and participant adherence. Weekly meetings before or after exercise sessions with the volunteers were therefore conducted in order to identify and address problems that they may have encountered.

### 3.6. Schematic layout of Research Design Phase I and Phase II

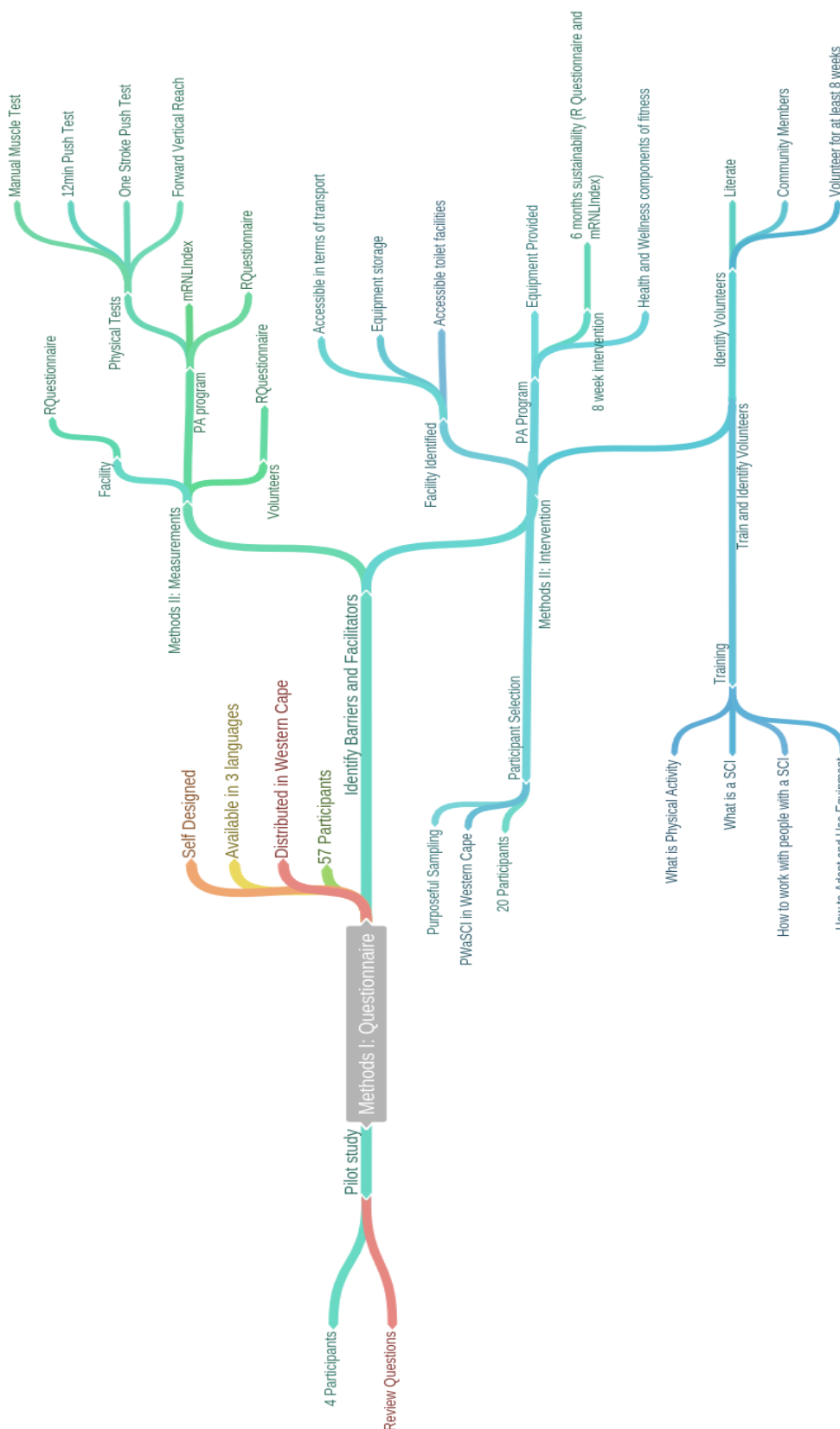


Figure 3: Schematic representation of the study

### 3.7. Methods Phase I: Determining the Barriers and Facilitators

#### 3.7.1. Timeline for Executing the Methods

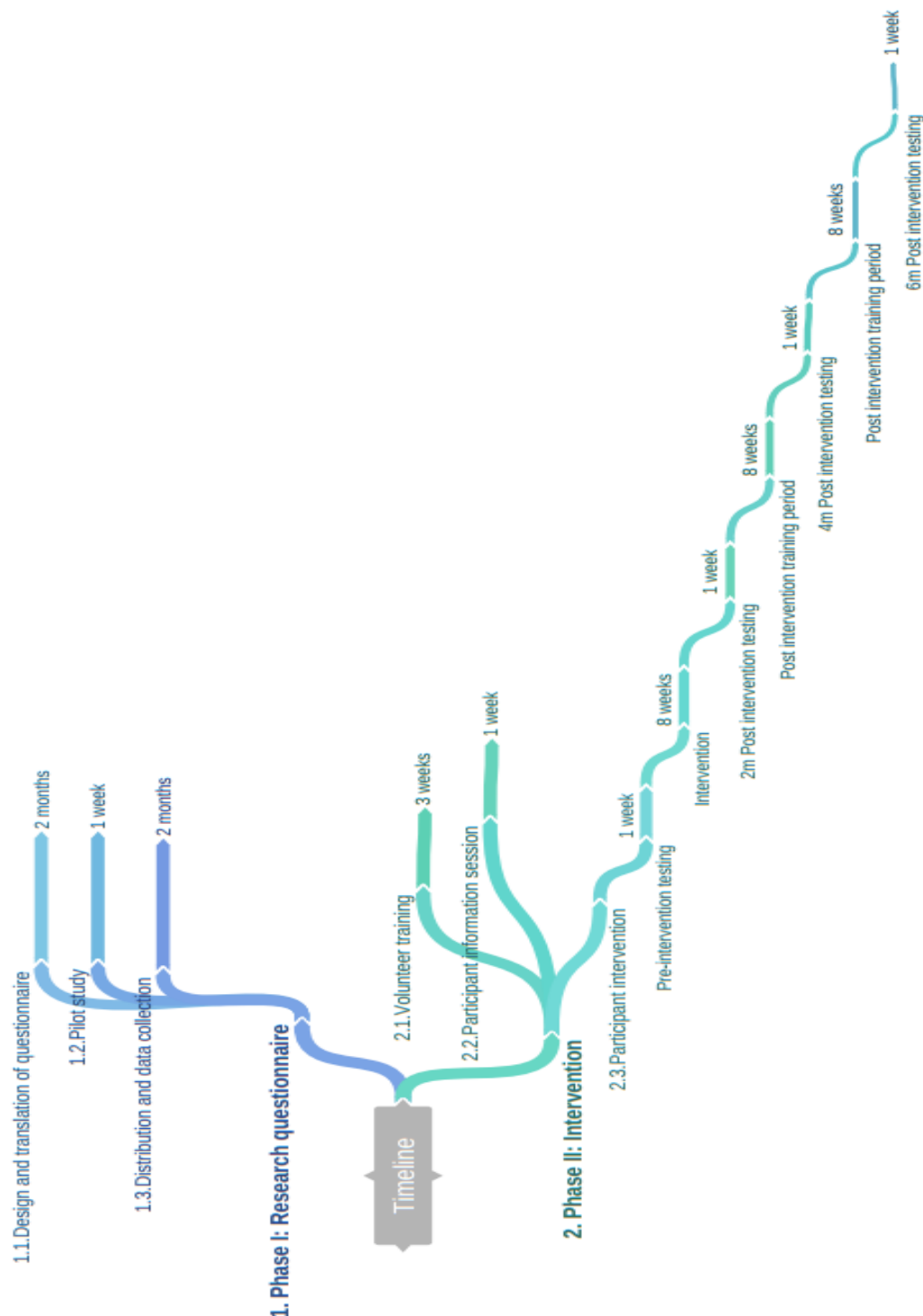


Figure 4: Timeline for executing the methods

### 3.7.2. Research Design and Data Collection Method

A descriptive research design was used in order to collect data on the barriers and facilitators faced by PWaSCI. A self designed research questionnaire was employed and was based on an extensive literature review on the barriers and facilitators faced by PWaSCI and PWD from different countries. The review included studies from focus groups (Rimmer *et al.*, 2004), semi-structured interviews (Conchar *et al.*, 2014), surveys (Scelza *et al.*, 2005) and questionnaires (Jaarsma *et al.*, 2014). The research questionnaire was used to gather as much as possible input and responses from different individuals within the Western Cape. Although interviews are suggested for subject matters that are under researched and where individual experiences and perspectives are required (Richardson, Papathomas, Smith and Goosey-Tolfrey, 2015), in this instance interviews would have limited the amount of participants in the initial data gathering process of Phase I of the study. In order to get individual experiences and perspectives additional lines were provided on the research questionnaire in order to capture any additional barriers or facilitators that were not mentioned. This proved to be successful as the participants in Phase II of the study, did comment and provide additional facilitators and barriers as they appeared during the course of the intervention.

In table 15 on the next page the advantages and disadvantages of using a questionnaire are summarised.

**Table 15: The advantages and disadvantages of using a questionnaire to collect data (Libweb, nd).**

Advantages	Disadvantages
1. Practical	1. Is argued to be inadequate to understand some forms of information - i.e. changes of emotions, behaviour, feelings etc.
2. Large amounts of information can be collected from a large number of people in a short period of time and in a relatively cost effective way	2. Phenomenologist's state that quantitative research is simply an artificial creation by the researcher, as it is asking only a limited amount of information without explanation
3. Can be carried out by the researcher or by any number of people with limited affect to its validity and reliability	3. Lacks validity
4. The results of the questionnaires can usually be quickly and easily quantified by either a researcher or through the use of a software package	4. There is no way to tell how truthful a respondent is being
5. Can be analyzed more 'scientifically' and objectively than other forms of research	5. There is no way of telling how much thought a respondent has put in
6. When data has been quantified, it can be used to compare and contrast other research and may be used to measure change	6. The respondent may be forgetful or not thinking within the full context of the situation
7. Positivists believe that quantitative data can be used to create new theories and / or test existing hypotheses	7. People may read differently into each question and therefore reply based on their own interpretation of the question - i.e. what is 'good' to someone may be 'poor' to someone else, therefore there is a level of subjectivity that is not acknowledged



8. There is a level of researcher imposition, meaning that when developing the questionnaire, the researcher is making their own decisions and assumptions as to what is and is not important. Therefore they may be missing something that is of importance
- 

### 3.7.3. **The Pilot Study**

The pilot study was conducted to test the questions in the research questionnaire and whether the questions were easy to understand/comprehend.

Four PWaSCI from different backgrounds and social status were asked (three men and one woman) to complete the research questionnaire in order to ensure that persons from different academic levels and cultures were able to complete the questionnaire. Two completed the questionnaire in Xhosa, one in English and one in Afrikaans. The researcher was present during completion of the research questionnaire to answer any questions and assist where needed and to make notes on questions that were unclear. Following the pilot study a few minor changes were made to the research questionnaire. These included additional options to some of the questions such as adding a 0, and some of the symbols such as < and > were replaced by descriptions of these symbols. Overall the participants agreed that the research questionnaire was easy to understand and to complete.

### 3.7.4. **Research Questionnaire**

The research questionnaires were made available in three different languages namely English, Afrikaans and Xhosa. The questionnaires were distributed to PWaSCI within the Western Cape using different agents. One agent was the Program Manager of the SCI Program of Senecio who gave hard copies to its members and assisted the participants in completing the questionnaire. The questionnaires were returned to the respective agent who submitted it to the principle investigator. The second agent or facility that was used was the Western Cape Rehabilitation Centre. The study was advertised locally at the Western Cape Rehabilitation Centre through posters and persons who wanted to complete the questionnaire collected a hard copy at the facility. Copies were returned directly to the principal investigator on the premises. The principal investigator was on the premises when the questionnaires was made available and assisted the participants where needed.

## **3.8. Methods Phase II: Removing the Barriers to Physical Activity**

### **3.8.1. Research Design and Data Collection Method**

During the second phase of the study a mixed method approach was implemented, which refers to both descriptive and experimental measurements being taken. Quantitative and qualitative data were collected in the form of physical testing, the condensed version of the research questionnaire and the mRNLI questionnaire.

### **3.8.2. The Intervention**

The second phase of the study included the intervention which started in Autumn (March) and ended in Spring (September). The intervention consisted of three parts namely selecting the right training environment, training and educating the volunteers and lastly the design and implementation of the exercise program in the different training environments.

### **3.8.3. Training Environment Selection**

In order to conduct the research suitable training venues/facilities were identified in order to run the PA program. The facilities were identified with the help of the different agents mentioned in section 3.5.1.1. Three different training environments were identified, namely the Health and Wellness Centre (HWC) at WCRC (formal exercise setting) in Mitchell's Plain Khayelitsha, the Civic Centre in Macassar (community based setting) and a church in Strand (community based setting). All the identified facilities had to comply with the following criteria below.

#### **Inclusion Criteria:**

1. Fully accessible in terms of access (entrance/exit to venue) and use of toilet facilities
2. Easily accessible in terms of road use/transport, distance and location
3. Not located at the top or bottom of a hill
4. Facility must be big enough to host the number of persons per exercise group and their assistive devices
5. Storage facility available for equipment

#### **3.8.3.1. The Training Environments**

##### **Environment 1: WCRC Group**

The HWC at the WCRC is an already established gymnasium within the community of Mitchell's Plain. The facility caters specifically for persons with disabilities in terms of accessibility and adaptive equipment. It is situated close to one of the main roads, which makes it easily accessible by road or other means of transport.



a



b

**Figure 5a and 5b: WCRC facility and equipment**

### **Environment 2: Community Group**

The Community group facilities were identified with the assistance of the program manager of Senecio, who was already involved in these two communities.

The Civic Centre in Macassar was a community hall that is used by people for different activities. For example the facility is used as crèche on a daily basis. The hall was made available for the PA groups twice a week for two hours. The hall was easily accessible in terms of access and toilet facilities. It was also located close to the main road in Macassar. The facility had basic exercise equipment for the PA program and an onsite storage facility was made available which made it possible to store the equipment on site.



a



b

**Figure 6a and 6b: Macassar Community facility**

The Church in Strand was also a venue that was frequently used by other members within the community. For example it was also used by a crèche on a daily basis and was made available to the exercise group twice a week for 2 hours per day. The church was easily accessible in terms of access to the hall and toilet facilities. The church was situated within the community and also easily accessible by road and close to the main road within Strand. The facility was equipped with basic exercise equipment and an onsite storage facility made it possible to store the equipment.



**a** **b**  
**Figure 7a and 7b: Strand Community facility and equipment**

### 3.8.4. Volunteer Recruitment and Training

Community volunteer workers (CVW) were recruited before the start of the intervention with the help of the agents and the participants. The agents and participants identified potential volunteers within their families and communities based on the inclusion criteria stipulated below. The identified volunteers were contacted telephonically by the principle investigator to confirm whether they met the inclusion criteria. Once this was confirmed they were asked whether they would be interested to volunteer. If they agreed they qualified for the training process. All the volunteers (n=8) that were identified met the inclusion criteria and therefore qualified to partake in the training process (3 x 4 hours).

#### CVW Inclusion Criteria

1. Had to be a resident in the local community
2. Have basic primary education (be able to read and write)
3. Person must be able to volunteer for 4 hours per week (2 hours per day, 2 days per week)
4. Had to commit for at least two months to the programme (for the pre-to two months post-intervention period)

Between two and five volunteers were initially recruited per group. The number of volunteers was determined by the sample size of each intervention group and the number of tetraplegics or paraplegics in each group. A ratio of one to three was used as guidance for tetraplegics and 1:2 ratio was used as a guide to recruit volunteers for paraplegics. Each group had two main volunteers that were in charge of running the session and additional volunteers were there to assist participants and main volunteer where needed.

### **3.8.4.1. Volunteer Assignment to the Different Training Environments**

#### **Environment 1: WCRC group**

At the HWC, four Biokinetics students from the University of the Western Cape (UWC) were assigned as volunteers to assist the Biokineticist at the HWC in running the PA program. This was in partial fulfilment of their practical training required by their University programme.

#### **Environment 2: Community group**

At Macassar two main volunteers and one assistant were selected. The one main volunteer was a friend to one of the participants and the other one a family member. The assistant was also a family member of one of the participants. During the course of the intervention all volunteers remained present. However, after the initial eight week intervention the one main volunteer had to quit due to personal responsibilities at home. She was not replaced as the initial agreement was that the volunteers had to stay on for at least eight weeks. There were no tetraplegics in the group and therefore enough volunteers remained to continue to run the program successfully.

At Strand two main volunteers and three assistants were selected. One of the main volunteers was a SCI patient who recovered from the injury, and the other was a family member of one of the participants and ex carer. The one assistant was a friend of one of the participants and the other two assistants were people who sustained a different type of injury and were physically able to assist. All the volunteers remained throughout the intervention.

### **3.8.4.2. Volunteer Training**

CVW training and education took place before the start of the intervention and was provided by the principal investigator. Theoretical (APPENDIX J) and practical sessions were covered in the training and included information about:

1. SCI and how to identify any problems in terms of secondary health conditions
2. How to work with PWaSCI
3. How to use adapted equipment/how to adapt equipment to the needs of the patient
4. How to handle and follow the emergency procedure in the event of an injury  
(APPENDIX M)

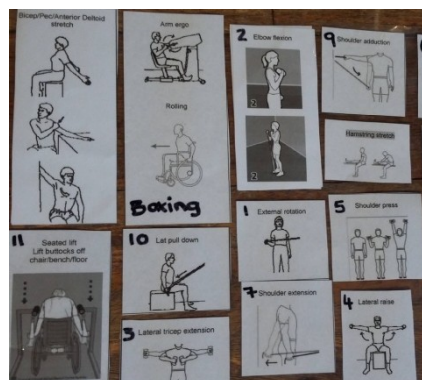
The sessions were conducted over three Friday mornings (09:00-13:00). One session per group covered the practical aspects and one session per group the theoretical aspects of the above mentioned. An additional session was added to recap the theoretical aspects and provide additional practical training where needed.

Ongoing training and support was provided by the principal investigator in the form of weekly and monthly meetings. The meetings also served as an opportunity for volunteers to report any difficult cases or any problems they might have as well as identify areas where additional education or training was needed.

The key role of each volunteer was thus to be a link between participants in the community and a healthcare professional (principal investigator). Additional tools provided to equip the volunteers to run the program in the community can be seen in figures 8 and 9. In figure 8 the Bio-Glove hand straps were provided to assist the tetraplegics with grip in order to complete some of the exercises and in figure 9 the specific exercises were provided to the volunteers to demonstrate the movement.



**Figure 8: Hand straps for Tetraplegics**



**Figure 9: Program exercises**

### 3.8.5. Intervention: Implementing the Exercise Activity Program

#### 3.8.5.1. Research Procedures

##### VISIT 1: Information Session

Participants met at their respective venues where the protocol and aims of the study were explained by the principal investigator. The participants were asked basic screening questions (APPENDIX K) pertaining to their health. The purpose of the basic screening was to familiarise the participants with the questions they would be asked before each session and to ensure that it is safe for them to partake in exercise. The participants were then asked to complete the informed consent (APPENDIX B) and provide proof of medical clearance for exercise testing and exercise participation if requested after the initial risk stratification process (completion of the PAR Q and YOU Questionnaire). Lastly the participants were informed about the testing procedures and given a chance to withdraw from the study should they wish to.

**VISIT 2: Testing**

During this visit the participants were asked the basic screening questions and given an explanation of rate of perceived exertion (RPE; APPENDIX D ) measuring scale as well as a quick overview of the tests that will be performed (APPENDIX E, F, G, H and I). The test batteries were conducted in the same venue as the intervention.

**VISIT 3-19: Intervention**

Participants were asked to come to the training venue two times per week for eight consecutive weeks. During this period the principal investigator was very involved in monitoring the participants as well as giving assistance to the trained volunteers where needed. After the eight week intervention the principle investigator became less involved and the volunteers were expected to run the program. This was done in order to determine whether the program could be successfully run by the volunteers in order to determine sustainability without constant support. Details on the exercise programme are in table 16.

**VISIT 20: Two Month Post-intervention Testing**

Following the last exercise session, the initial testing procedures was again explained and the participants completed the condensed version of the research questionnaire (barriers and facilitators faced during the intervention), the mRNLI (APPENDIX I) as well as the physical test batteries (APPENDIX E, F, G, H).

**VISIT 21 and 22: Four and Six Month Post-intervention Tests**

Four months after the initial eight week intervention a follow up was scheduled to evaluate the program through completion of the physical test batteries and sustainability through the condensed version of the research questionnaire for participants (APPENDIX A) and the mRNLI questionnaire (APPENDIX I). After six months the participants completed the condensed version of the research questionnaire for the last time. This was done in order to test sustainability and whether the barriers that were removed prior to the intervention was successful at helping the participants remain PA over the six month period following the eight week intervention.

### **3.9. Procedures and measurements**

#### **3.9.1. Physical Test Battery**

Quadriplegic and Paraplegic tests:

1. 12 min push test (APPENDIX E)
2. One stroke push task (APPENDIX F)
3. Forward vertical reach (APPENDIX G)
4. Manual muscle testing (APPENDIX H)
  - a. Deltoids (anterior, middle and posterior aspect)
  - b. Adductors (Latissimus dorsi)
  - c. Triceps
  - d. Biceps
  - e. Internal and external rotators
  - f. Wrist flexors and extensors

#### **3.9.2. Questionnaires**

1. Modified Reintegration to normal living index (mRNLI) (APPENDIX I)
2. Research Questionnaire (APPENDIX A)

#### **3.9.3. Exercise Program**

Exercise equipment was made available within the different communities and included, chairs, mats, ankle weights, dumbbells, rubber bands and tubes, sticks, Swiss balls and medicine balls.

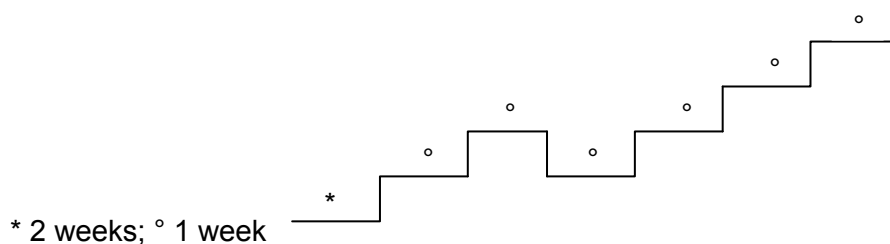
All the groups underwent two exercise sessions per week. Each session lasted about 80-100 min each. Exercise sessions consisted of a combination of cardiovascular, resistance, functional and flexibility exercises. The type and intensity of the exercise session was dependent on the information gathered from each participant and their abilities. The program is summarised in table 16 on the next page.



**Table 16: The basic layout of the exercise program**

Type of Exercise	Duration (min)	Repetition	Frequency
<b>Cardiovascular</b>			
<ul style="list-style-type: none"> <li>• Arm ergometry / rolling / boxing / combination</li> </ul>	10-20		Twice / week
<b>Resistance</b>			
<ul style="list-style-type: none"> <li>• Dumbbells</li> <li>• Elastics / tubes</li> </ul>	15-20		Twice / week
<b>Functional exercises</b>			
<ul style="list-style-type: none"> <li>• Balance</li> <li>• Mat exercises</li> <li>• Chair lifting</li> <li>• Weight shift</li> <li>• Finding centre of gravity</li> </ul>	10-15	2 x 10 (varied each week)	Twice / week
<b>Flexibility</b>			
<ul style="list-style-type: none"> <li>• Stretching the muscles of the anterior shoulder, the hamstrings and hip flexors</li> </ul>	5		Twice / week

Periodization was used to increase the intensity of the program over the eight weeks either in the form of increased repetitions, sets or weight. The step formation was to be used (Fig. 10).

**Figure 10: Periodization of the exercise program**

The first line represents two weeks, there after every step represent one week. The initial two weeks aimed to familiarise the participants with exercise and not to increase the intensity too quickly causing possible delayed onset muscle soreness (DOMS), which may affect ADL and ultimately participant adherence. Each week the intensity of the program was increased either by the number of sets, the number of repetitions or by increasing the weight used as seen in table 17.

**Table 17: Periodization of the physical activity program**

<b>Week</b>	<b>Set</b>	<b>Repetition</b>	<b>Weight</b>
1 and 2	2	10	Dependent on patient
3	3	10	
4	3	12	
5	2	10	
6	3	10	Increase weight by 500g-1000g
7	3	15	
8	3	15	Increase weight by 500g-1000g

Volunteers were asked to keep a log book of each exercise session. This information included reasons why participants missed sessions, when they missed sessions and whether incidents occurred.

### 3.9.4. Outcome Variables during the Tests and Exercise Sessions

#### 3.9.4.1. Reintegration to Normal Living Index (RNLI)

This index was selected to measure the participant's satisfaction with his/her level of community participation. It aims to measure participation and assesses quantitatively the degree to which individuals who have experienced traumatic or incapacitating illness achieve reintegration into normal social activities.

The questionnaire used 11 declarative states and focused on seven domains. The first 8 items represent 'daily functioning' and the remaining 3 items represent 'perception of self.' The seven domains included indoor and community and distance mobility, self care, daily activities (work and school), recreational and social activities, family roles, personal relationships and presentation of self to other and general coping skills (Wood-Dauphinee, Opzomer, Williams, Marchand and Spitzer, 1988).

Each domain is accompanied by a visual analogue scale (VAS, 0 to 10); the VAS is anchored by the statements, "does not describe my situation" (1 or minimal integration) to "fully describes my situation" (10 or complete integration). The scoring was done by adding the total together and calculating the percentage. A maximum score of a 100 could be obtained.

The questionnaire has good concurrent and construct validity. It also has an internal consistency of  $r = 0.9$  (Wood-Dauphinee, Opzoomer, Williams, Marchand and Spitzer, 1988). The consistency, however, is reduced when patients and significant others fill in the forms ( $r = 0.62$ ) and when health care professionals and the patient fill in the form ( $r = 0.39$ ) (Wood-Dauphinee, Opzoomer, Williams, Marchand and Spitzer, 1988). In this study the patients completed the form, however, the principle investigator was present to assist where needed.

#### **3.9.4.2. Changes to Reintegration to Normal Living Index (mRNLI)**

Due to the lack of access to the original questionnaire the modified Reintegration to Normal living Index (mRNLI) was used. The mRNLI uses a four point ordinal scale.

- 0 – Does not describe me or my situation
- 1 – Sometimes described me or my situation
- 2 – Mostly described me or my situation
- 3 – Fully describes me or my situation

The mRNLI was also used in this study to accommodate for various comprehension levels of different population groups, as it was found in previous research that the 10 point VAS to be too difficult to comprehend. Examples of research using the four point scale include Bourdeau *et al.* (2008) who conducted their research in older adults discharged from inpatient rehabilitation and Mothabeng (2011) who administered the questionnaire in South Africa in PWaSCI.

#### **3.9.4.3. Manual Muscle Test (MMT)**

MMT was selected as a means to test different functional movements as it gives an indication of how strong the individual was based on a score of 0 to 5. Muscle testing is an important component of the physical assessment. The MMT test can easily be administered and is a standardized assessment that measures muscle strength (Herbison, Isaac, Cohen and Ditunno, 1996).

Resistive tests were performed on selected muscles (functional movements) in the arms and the tests were performed in the individual's wheelchair. The following functional movements were tested, namely shoulder flexion and extension, shoulder abduction and adduction, shoulder internal and external rotation, elbow flexion and extension and wrist flexion and extension. The muscles were graded on the five-point ordinal scale described below.

**The five-point scale was defined as:**

- 0-Complete lack of voluntary muscle contraction. The examiner is unable to feel or see any muscle contraction.
- 1-Faint or “flicker” muscle contraction without any movement of the limb. The examiner can see or palpate some contractile activity of the muscle/s or may be able to see or feel the tendon “pop up” or tense as the athlete tries to perform the movement.
- 2-Very weak muscle contraction with movement through complete range of motion in a position that eliminates or minimizes the force of gravity. This position is often described as the horizontal plane of motion.
- 3-Muscle can complete a full range of motion against only the resistance of gravity.
- 4-Able to complete the full range of motion against gravity and can tolerate strong resistance without breaking the test position. The Grade 4 muscle clearly breaks with maximal resistance.
- 5-Able to complete full range of motion and maintain end point range position against maximal resistance. The examiner cannot break the athlete’s hold position.

The test has an excellent interrater reliability of ICC = 0.94, however, validity has not been established (Herbison, Isaac, Cohen and Ditunno, 1996). The tests were conducted by the principle investigator at all the test points.

**3.9.4.4. One-Stroke-Push Task (1 stroke PT)**

The test was selected as it is one of the more common tests used in SCI to test functional ability as well as power. The aim of the test was to assess functional ability in an everyday common task that requires strong effective propulsion.

The test was administered on the indoor surface of each facility (modified from the original version in APPENDIX F) and the distance pushed was measured in cm. With all 4 wheels positioned on the surface, the participant propelled the wheelchair forward by pushing once with maximal effort. Hand placement to begin propulsion was at the discretion of the participant. The most posterior point of the rear wheels was marked as the starting point (a meter stick with a carpenter’s level was used to ensure accuracy). Once the wheelchair rolled to a stop, the most posterior point of the rear wheels was marked to indicate the completed distance pushed. If the push was asymmetrical, the mark was recorded for the most posterior rear wheel. The distance (cm) between the two marked points was recorded.

The test has an excellent test-retest reliability of  $r = 0.99$ , however, no results have been reported on the validity of the test in PWaSCI (May *et al.*, 2003). The test was conducted by the principal investigator and the participants were given two opportunities and the best score was recorded.

#### **3.9.4.5. Forward Vertical Reach Test (Fwd VR)**

The test was selected as it is one of the more common tests used in SCI to test functional ability as well as flexibility. The test assesses functional ability in an everyday common task that requires lifting of upper extremities.

The test was performed by positioning the wheelchair parallel to the marking board, and the participants held a measuring stick, independently or with cuff supports, using both hands (palms down). The 1m measuring stick had a felt pen attached to one end and a carpenter's level secured in the middle. The tip of the felt pen was positioned within 2.54 cm of the marking board. Participants began with forearms parallel to their thighs and raised the measuring stick upward. Participants were instructed to keep the measuring stick level and to avoid excessive backward arching. A dot was made with the felt pen on the marking board at the highest point reached. The distance in centimeters from the floor to the dot was measured.

The test has an excellent test-retest reliability of  $r = 0.99$ , however, no results have been reported for the validity of the test in PWaSCI (May *et al.*, 2003). The tests were conducted by the principle investigator and two efforts were given to each participant. The best of the two efforts were recorded.

#### **3.9.4.6. 12 min-Push Test (12min PT)**

The 12 min push/aerobic test was selected as it is easy to administer and requires little equipment. The aim of the test was to determine cardiovascular capacity of the participants.

**Table 18: How to administer the 12 min-Push Test (Vanderthommen *et al.*, 2002)**

Equipment	Procedure	Scoring
<b>400 m running track</b>	1. Place markers at set intervals around the track (e.g. every 50m) to aid in measuring the completed distance.	Record the completed distance to the nearest 100 meters.
<b>Measuring tape</b>	2. Participants wheel around the track for 12minutes and the distance covered is recorded.	
<b>Recording sheets</b>	3. The participants must be encouraged to push themselves as hard as they can.	

**Table 19: Guidelines for interpreting test results (Vanderthommen *et al.*, 2002)**

Rating	Distance (miles)	Distance (meters)	Estim. VO <sub>2</sub> max (ml/kg/min)
<b>Excellent</b>	>1.59	> 2560	> 36.2
<b>Above average</b>	1.36-1.59	2171 – 2560	29.2 – 36.2
<b>Average</b>	0.87-1.35	1381 – 2170	14.6 – 29.1
<b>Below average</b>	0.63-0.86	1010 – 1380	7.7 – 14.5
<b>Poor</b>	<0.63	< 1010	<7.7

The reliability of the test is dependent on practice, pacing and motivation (which was provided by the principal investigator who administered the test). If these are addressed there is a good reliability (Wood, 2008). Validity for the test has not been established. Reliability of the test was ensured by familiarizing the participants with the test prior to the test and during the test the principle investigator continuously motivated the participants.

#### **3.9.4.7. Changes to the 12 min Push Test**

Modifications were made to the original 12 min push test in order to accommodate for the lack of resources within certain communities. The test was modified by using a figure eight course of 10 m x 10 m (a total lap distance of 48m) instead of a 400 m track to test for cardiovascular endurance. The participants still had to complete the course as many time as possible within 12 min. The rest of the protocol remained the same.

### 3.9.5. Data Collection Procedures

The battery of data collection instruments was administered by the principal investigator at pre-intervention, 2 and 4 months post-intervention. The tests were administered in the following order, first the manual muscle tests were conducted followed by the forward vertical reach test and the one stroke push task and finally the 12 min push test. The principal investigator also filled in the questionnaires for the participants and this was done to eliminate any disparities such as the functional literacy of each participant. It was anticipated that most of the participants were from disadvantaged communities and therefore may not have the necessary experience in completing self administered questionnaires (Westaway Olorunju and Rai, 2007). The principal investigator also completed the questionnaires in order to standardise the data collection and clear up any confusion regarding questions. The test batteries were also conducted by the principal investigator in order to ensure the tests were performed identically at each occasion Assistants did, however, assist in measurements and with the recording of the data. The assistants received proper training in the specific measurement techniques used prior to the commencement of the testing.

## CHAPTER 4

### RESULTS AND DISCUSSION PHASE I

#### 4.1. Introduction

In this chapter the results of the qualitative phase (phase I) of the study are presented. The primary aim of Phase I was to identify the barriers that prevent PWaSCI from being physically active. The objectives were to:

- Identify personal/individual barriers and facilitators
- Identify social barriers and facilitators
- Identify environmental barriers and facilitators
- Identify program/policy barriers and facilitators

#### 4.2. Socio Demographic and Injury Profile

Before the results of the questionnaire are presented, the socio demographic and injury profiles of the participants are firstly considered. A summary of these results are presented in table 20. A total of 57 persons with a spinal cord injury (PWaSCI) completed the research questionnaire. The gender distribution of the participants was 49 men and eight women (ratio 6:1). The average age of the participants was 38 years, with the youngest participant being 20 and the oldest was 84 years old ( $\pm 13$  SD). The majority of the participants were in their twenties ( $n=15$ ). Twenty-nine of the participants were coloured, 25 were black, two white and one was Indian.

The majority of the participants were paraplegics (35/57). Most of the participants sustained their injuries through violence (44%). Gunshot or stab wounds (37%) represented most of the reported violent crimes. The causes for gunshot/stab wounds ranged from personal violence, to robberies and gang fights. The additional seven percent was due to blunt trauma. Motor vehicle accidents accounted for 19% of the injuries. Eleven percent of the injuries were caused by sporting accidents such as a shallow water diving accident and nine percent were due to Tuberculosis (TB) of the spine. Most of the participants were hospitalised within the Western Cape after their injury, with only four percent being hospitalised in the Eastern Cape. Fifty-five of the participants were hospitalised in government hospitals and only two PWaSCI were hospitalised in private hospitals.



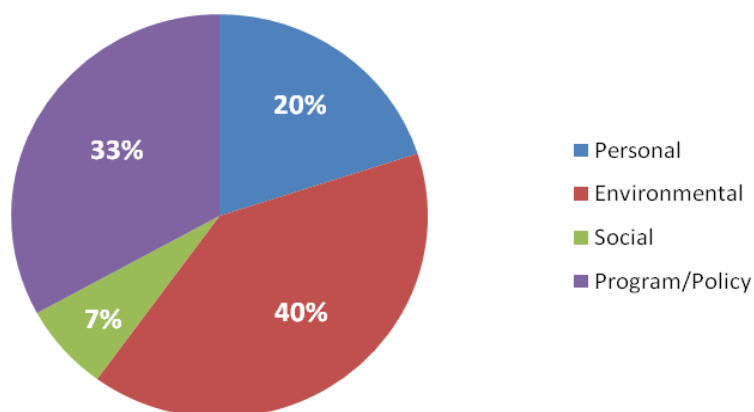
**Table 20: The socio-demographic and injury profile of persons with a spinal cord injury**

<b>Participant Profile</b>	<b>n = 57</b>	<b>%</b>
<b>GENDER</b>		
Men	49	86
Women	8	14
<b>AGE</b>		
Mean	38	/
Range	20-84	/
<b>ETHNICITY</b>		
Black	25	44
Coloured	29	50
White	2	4
Indian/Asian	1	2
<b>TYPE OF INJURY</b>		
Tetraplegic	22	39
Paraplegic	35	61
<b>CAUSES</b>		
Motor vehicle accident	11	19
Violence	25	44
Sport accident	6	11
*TB Spine	7	12
Other	8	14
<b>HOSPITALISATION</b>		
Private	2	4
Government	55	96
*TB Spine: Tuberculosis of the spine		

### 4.3. Barriers to Physical Activity Participation

The barriers that were identified in the research questionnaire were categorised according to the Theory of Planned Behaviour (TPB) into personal/individual, environmental, social and program/policy barriers (Fig. 11). The barriers are reported as the total number of barriers that were reported by the participants and not according to the number of participants. Each participant was allowed to select as many barriers as they felt impacted them. Most of the barriers that were reported in the questionnaire were environmental barriers 40% (n=115),

with personal barriers representing 33% (n=95) of the total barriers. Program/policy barriers were reported as 20% (n=59) of the barriers and social barriers accounted for seven percent (n=20).



**Figure 11: Prevalence of barriers to physical activity**

#### 4.3.1. Personal Barriers

The most frequently reported personal barrier (Table 21) was the injury level of the participants and was reported as 34% of the total barriers identified. The second most reported personal barrier was secondary conditions (17%). The rest of the barriers were lack of finances (14%), lack of skill/fitness (13%) and lack of knowledge (14%). Interestingly only five percent of the barriers were lack of time as a personal barrier to physical activity. The remaining, less prevalent barriers included being at work and being in a comfort zone (2%).

**Table 21: Prevalence of personal barriers to physical activity**

Personal barrier	%	(n)
Injury level (Tetraplegic/Paraplegic)	34	32
Secondary conditions	17	16
Lack of finances	14	13
Lack of skill	15	14
Lack of knowledge	14	13
Lack of time	5	5
Other	2	2
<b>Total</b>	<b>100</b>	<b>95</b>
<b>n = total number of barriers</b>		

#### 4.3.2. Environmental Barriers

Lack of transport was considered the primary environmental barrier (30%), followed by lack of facilities (28%), weather conditions (15%) and lack of adaptive equipment (12%) (Table 22). Eight percent of the responses indicated that facilities were inaccessible and five percent of the identified responses felt that facilities were in inconvenient locations.

**Table 22: Prevalence of environmental barriers to physical activity**

<b>Environmental Barrier</b>	<b>%</b>	<b>n</b>
Lack of facilities	28	32
Inaccessible facilities	8	9
Inconvenient location	5	6
Lack of adaptive equipment	12	14
Lack of transport	30	35
Weather	15	17
Other	2	2
<b>Total</b>	<b>100</b>	<b>115</b>
<b>n = total number of barriers</b>		

#### 4.3.3. Social Barriers

The most common reported social barrier was lack of information received about PA from therapists upon discharge from the rehabilitation facility (50%) (Table 23). Twenty percent of total barriers mentioned by the participants regarded lack of family and friend support as a barrier, while 15% of the barriers represented lack of role models as important. Negative societal attitudes accounted for 10% of the total social barriers that were reported.

**Table 23: Prevalence of social barriers to physical activity**

<b>Social Barrier</b>	<b>%</b>	<b>n</b>
Lack of family support	20	4
Negative societal attitudes	10	2
Lack of role models	15	3
Lack of information received	50	10
Other	5	1
<b>Total</b>	<b>100</b>	<b>20</b>
<b>n = total number of barriers</b>		

#### 4.3.3.1. Program/Policy Barriers

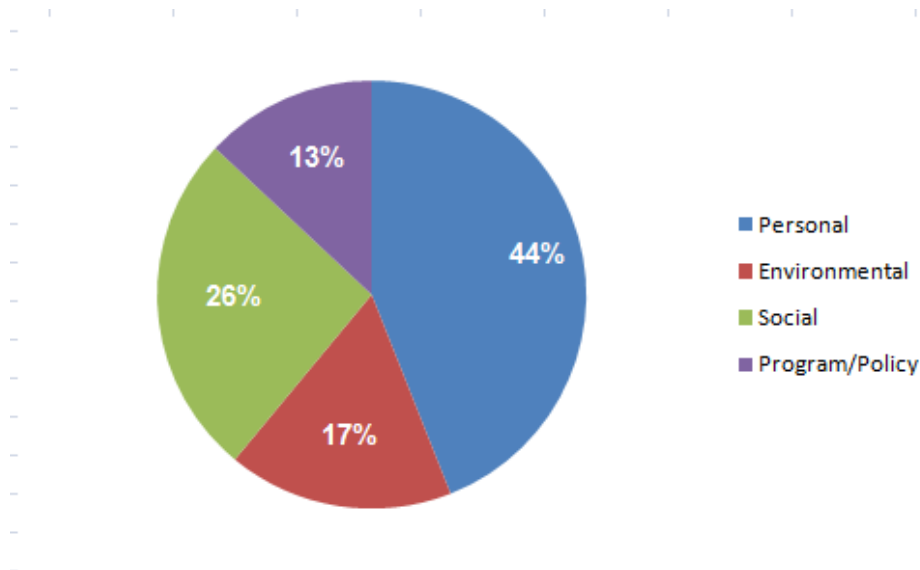
The major barriers that were identified under program/policy barriers were lack of trained volunteers (32%) and lack of appropriate programs (32%) (Table 24). Cost of programs was reported in 17% and lack of staff capacity as 14% of the total barriers identified by the participants. Lack of guidance by staff (3%) and negative attitudes from staff (2%) were not considered major barriers.

**Table 24: Prevalence of program/policy barriers to physical activity**

<b>Program Barrier</b>	<b>%</b>	<b>n</b>
Lack of appropriate programs	32	19
Cost of programs	17	10
Lack of staff capacity	14	8
Lack of trained volunteers	32	19
Lack of guidance by staff	3	2
Negative attitudes	2	1
Other	0	0
<b>Total</b>	<b>100</b>	<b>59</b>
<b>n = total number of barriers</b>		

#### 4.4. Facilitators to Physical Activity Participation Identified by Persons with a Spinal Cord Injury

The facilitators that were identified in the research questionnaire were also categorised according to the Theory of Planned Behaviour (TPB) into personal/individual, social, environmental and program/policy facilitators. The facilitators were also reported as the total number of facilitators that were identified by the participants. The majority of facilitators fell under personal, 44% (n=142), with social facilitators representing 26% (n=84) and environmental 17% (n=57) and program/policy 13% (n=43) of the total facilitators.



**Figure 12: Prevalence of facilitators to physical activity**

#### 4.4.1. Personal Facilitators

The most reported facilitator was the fact that people enjoyed and felt good when they exercised (35%) (Table 25). The desire to be active and fit was the second highest facilitator (33%), while 26% regarded improvement of their self esteem as important. Other facilitators represented 6% of the responses and included to improve their condition, to stay positive and wanting to do something.

**Table 25: Prevalence of personal facilitators to physical activity**

Personal Facilitators	%	n
Desire to be active	33	35
Improve self esteem	26	28
Feel good/enjoy it	35	37
Other	6	6
<b>Total</b>	<b>100</b>	<b>106</b>

**n = total number of facilitators**

#### 4.4.2. Environmental Facilitators

The most frequently reported environmental facilitator was accessible facilities (44%) and the fact that the training facilities were in safe locations (33%) (Table 26). Fourteen percent of the identified facilitators regarded transport as a facilitator and 7% indicated that new facilities in rural areas were facilitators.

**Table 26: Prevalence of environmental facilitators to physical activity**

<b>Environmental Facilitators</b>	<b>%</b>	<b>n</b>
Accessible facilities	44	25
New facilities in rural areas	7	4
Transport	14	8
Facility in safe location	33	19
Other	2	1
<b>Total</b>	<b>100</b>	<b>57</b>
<b>n = number of facilitators</b>		

#### 4.4.3. **Social Facilitators**

As seen in table 27 the most important social facilitator was support (45%) by friends and family members. The second most important facilitator was positive encouragement from peers with disabilities (27%) Role models were reported as 13% by the respondents as a facilitator, while 7% received adequate information from therapists regarding PA. Positive societal attitudes contributed 7% to the total facilitators.

**Table 27: Prevalence of social facilitators to physical activity**

<b>Social Facilitators</b>	<b>%</b>	<b>n</b>
Family support	45	38
Positive encouragement from peers with a SCI	27	23
Positive societal attitudes	7	6
Role models	13	11
Adequate information	7	6
Other	0	0
<b>Total</b>	<b>100</b>	<b>84</b>
<b>n = number of facilitators</b>		

#### 4.4.4. **Program/Policy Facilitators**

The program/policy facilitators are summarized in table 28. The program or policy facilitators were much less reported on. It was reported that more and better quality programs (28%) and skilled staff (28%) helped PWaSCI to be physically active. Trained volunteers (23%) and enough staff (19%) were also mentioned as facilitators.

**Table 28: prevalence of program/policy facilitators to physical activity**

<b>Program/Policy Facilitators</b>	<b>%</b>	<b>n</b>
Better quality programs	28	12
Skilled staff	28	12
Trained volunteers	23	10
Enough staff	19	8
Other	2	1
<b>Total</b>	<b>100</b>	<b>43</b>
<b>n = number of facilitators</b>		

## **4.5. Phase I Discussion**

### **4.5.1. Socio Demographic and Injury Profile**

Although a large amount of research has been conducted on the global epidemiology of SCI, very few studies have been done in developing countries and more specifically within South Africa. As mentioned in Chapter two there are no official statistics regarding the number of people living with a SCI in South Africa and this is mainly due to a lack of SCI based registries within South Africa (Mothabeng, 2011).

#### **4.5.1.1. Gender**

The study participants consisted of 49 men and 8 women (6:1 ratio). This is consistent with the data of O'Connor (2005) who found that men were more likely to sustain a SCI compared to women. However, the gender distribution in the current study was different to that found in previous literature in that the ratio for men to women was much higher. The majority of international literature reported a 4:1 ratio (men: women) (Wyndaele and Wyndaele, 2006; Livecchi, 2011). Consistent with the international literature is the study done by Mothabeng (2011) who found a 3.4:1 ratio. This possibly suggests that the women in this study population were underrepresented and one possible reason could be that women tend to be less involved in violent crimes and gang warfare, which was one of the major causes of injury within this study.

#### **4.5.1.2. Ethnicity**

The majority of the participants were coloured (n = 29; 50%) and 44% (n = 25) were black. This is consistent with the race profile of the Western Cape in that the majority of the population in the Western Cape is coloured (52%) and black (29%). White people only make

up 18% of the population and Indian/Asian 1% (Western Cape Department of Agriculture, 2014).

#### **4.5.1.3. Type of injury**

The injuries that were sustained mainly resulted in complete paraplegia (61%). Similar results were found by researchers in developing countries (Rathore, Farooq, Muzammil, New, Ahmad and Haig, 2008; Mothabeng, 2011) and developed countries (Wyndaele and Wyndaele, 2006; Rathore, 2010). In the review done by Wyndaele and Wyndaele (2006) the authors mentioned that there was a rise in the incidence of tetraplegia worldwide. They predicted an increase of 143% in the number of incomplete tetraplegia by the year 2021. This prediction was based on population growth, aging and the number of SCI that occurs within the elderly. This information was supported by Bryce *et al.* (2011) who stated that according to the American National SCI Database the more common injury was tetraplegia (50.5% tetraplegia vs. 44.1% paraplegia), with incomplete tetraplegia being reported as most frequent.

#### **4.5.1.4. Cause of Injury**

There are two main causes of a SCI, namely traumatic and non traumatic SCI. Traumatic causes are motor vehicle accidents (MVA), violence, sporting accidents and falls. Non traumatic causes include disease and birth defects.

In this study the majority of the participants sustained a traumatic SCI (74%). The most common cause for injury was some form of violence (n=25; 44%), with the majority of the participants reporting either being stabbed or shot. The second most common cause of a traumatic SCI was motor vehicle accident (MVA), 19% (n=11) followed by sporting accidents, 11% (n=6). In a study conducted in South Africa in 1994 by Hart *et al.* the most common cause of injury was reported as violence in the form of gunshot and stab wounds (56%), followed by road traffic accidents (25%) and fall from heights (2.4%).

Mothabeng (2011) considered that a possible reason for violence as the number one cause of injury in the study done Hart *et al.* (1994) may be related to the fact that the study was conducted in the pre democratic area when violence was on the rise due to the changing political and economic systems. However in their study, Mothabeng found MVA to be the major cause of SCI (71%). This is consistent with most of the literature in that the majority of the researchers report MVA as the major cause of SCI (Livecchi, 2011; Bryce *et al.*, 2011; Divanoglou and Levi, 2009). However, Lee, Cripps, Fitzharris and Wing (2014) stated that violence related SCI are most common in areas where there is conflict or a high availability of weapons resulting in gunshot wounds or stabbing. According to their study the majority of



violence was found in North and South America, Southern Africa and the Middle East, with South Africa reporting the highest incidence of gunshot injuries (Lee *et al.*, 2014).

The second most reported cause found by Mothabeng (2011) was violence and falls. They reported 19.4% cases of gunshot wounds. In the USA the second most common cause was falls (22%) followed by penetrating injuries, such as gunshot wounds (17%) and sports injuries (8%) (Livecchi, 2011). In the current study other traumatic causes accounted for 15% of injuries and included falling in the shower, falling from a height and cervical disk disorders. There were also a number of unknown causes (5%).

Non traumatic injuries accounted for 12% of the participants. Tuberculosis (TB) of the spine was the only reported disease resulting in either a complete or incomplete SCI. This is consistent with the research done by Mothabeng (2011) in that the most common cause for non traumatic SCI was due to TB. Turgut (2001) also found TB to be the most important cause of non traumatic SCI in the underdeveloped and developing world. Polley and Dunn (2009) found spinal TB in 16.3% of their participants and noted that TB of the spine is far more common than what was reported in the literature. TB is also very prevalent within the Western Cape and according to the Department of Health, Western Cape (2005) 48 000 people were registered with TB in 2005 (cited in Draper, Pienaar, Parker and Rehle, 2007).

#### 4.5.2. **Barriers**

There are various barriers that able bodied people and PWaSCI face. Identifying these barriers was crucial for optimal program development and implementation of a PA program within the community (Phase II). According to the data collected in the research questionnaire the most prevalent barrier were the environmental barriers. These included lack of transport, lack of facilities or accessible facilities that provide PA opportunities for PWaSCI. The least reported barriers were the social barriers and included aspects such as lack of support from friends and family and peers with disabilities and negative societal attitudes.

##### 4.5.2.1. **Personal Barriers**

The majority of the participants reported that their injuries were a barrier to PA. Since most of the participants were paraplegics this was the most reported barrier (22%). This is further supported by the fact that 12% of the reported barriers were also injury related and said that tetraplegia was a barrier. This finding seems inconsistent with the literature, as, to the researcher's knowledge, no previous study reported injury level as a barrier to PA. According to Tawashy, Eng, Lin, Tang, and Hung (2009) lesion level is not a PA determinant and it was

not found to be a barrier to PA in their study. A possible explanation for the results was the participants' perception of their abilities and a lack of knowledge about their abilities.

Other most common barriers reported were lack of finances, lack of skill/fitness and lack of knowledge. This was consistent with previous research listing lack of finances, lack of knowledge (Rimmer *et al.*, 2004; Crawford and Stodolska, 2008; Shakespeare and Kleine, 2013) and lack of skill (Tasiemski *et al.*, 2004b) as major barriers to PA. Lack of time, health issues and lack of knowledge were also some of the commonly reported barriers to PA in the able bodied population in South Africa (Louw *et al.*, 2012; Jaarsma *et al.*, 2014). Although there are some similarities between PWD and the able bodied population in terms of personal barriers, PWD face additional barriers and this should be taken into consideration when planning and implementing PA programs. Secondary complications made up 17% of the reported personal barriers and included bladder infections which comprised 50%, pain (19%), and pressure sores (31%) of the total secondary conditions. This is supported by research conducted by Van Den Berg-Emons *et al.* (2008) who found bladder infections to be a barrier and Silver, Ljungberg, Libin and Groah (2012) who reported co-morbid medical conditions to be major barriers. Secondary complications are often the cause of rehospitalisations and result in bed rest and further physical inactivity. It is therefore important that these barriers be eliminated in order to improve health and wellbeing by preventing acute and chronic co-morbidities (Silver *et al.*, 2012).

Lack of time, which is also a common barrier in the able bodied population (Jaarsma *et al.*, 2014) was also frequently reported by PWD (Stephens *et al.*, 2012; Henderson, 1995 in Crawford and Stodolska, 2008). In the current study lack of time was reported as 5% of the total personal barriers. This low number may be attributed to the high unemployment rate amongst the participants. In South Africa, according to the profile of persons with disabilities (Census, 2011), there is a low labour market absorption for persons with disabilities. Murphy (2011) also reported on literature suggesting high variability in employment rates. For example, in the USA Lidal, Huynh, and Biering-Sørensen (2007) found post injury employment rates ranged from 21%-67%. Although none of the participants indicated that work was a barrier to PA, various barriers prevent PWaSCI from working (Murphy, 2011).

#### **4.5.2.2. Environmental Barriers**

The most reported environmental barrier in most research within the developing and developed world is lack of transport, followed by lack of accessibility or lack of facilities (Scelza, 2005; Crawford and Stodolska, 2008; The Group Life, 2011; Silver *et al.*, 2012;

Jaarsma *et al.*, 2014). This is concurrent with the findings in this current study. Lack of transport was identified by most of the participants (59% of the barriers) as a barrier, followed by lack of, or no facilities to be physically active (52% of the total barriers) and inaccessible facilities (13% of the total barriers).

South Africa, in general, lacks an extensive and efficient public transport system, and this is especially true for PWD. Hence a lot of PWD, and more specifically PWaSCI, are dependent on their wheelchairs for transport. This leads to other variables, such as the weather, to become barriers to PA. This is especially problematic during the rainy season and during summer time when temperatures can exceed 30°C. PWaSCI are more susceptible to medical conditions such as colds, flu and pressure sores caused by wet clothing. They also have thermoregulatory problems, which could lead to overheating or even heat stroke. This further highlights the importance of having adequate transport. Inconvenient location (7%) was another barrier mentioned by a few participants and is also influenced by the lack of transport as people do not necessarily have the means to reach these locations.

Environmental barriers play a crucial role in either facilitating or impeding health in PWD. According to Rimmer and Rowland (2008) secondary conditions (personal barriers) are also exacerbated by environmental barriers as they prevent PWD from being physically active. Regular PA has the potential to enhance well being by contributing to the maintenance and recovery of health (Parschau *et al.*, 2012).

#### **4.5.2.3. Social Barriers**

The social barriers that were identified in this study included lack of information (13%), lack of friend/family support (4%) and lack of role models (2%). This is consistent with the research done by Stephens *et al.* (2012) and Malone, Barfield, Brasher and Ed (2012) who found that their participants did not receive adequate information regarding sporting opportunities. Magasi *et al.* (2008) also found that limited social support and family role functioning were barriers to participation. According to Scelza *et al.* (2005) many people think that because their doctors did not encourage them to be active that they may not benefit from PA. It is important for PWaSCI to be informed about PA as it affects overall well being (Putnam, Greenen, Powers *et al.*, 2003).

Negative societal attitudes were mentioned by 4% of the participants and were also identified as one of the barriers in promoting health in PWD in the study done by Rimmer *et al.* (2008). A possible reason for the low rate in this study could be due to the fact that most of the participants were already physically active in areas that cater specifically for PWD and

they did not need to interact much with society around them when they were physically active and therefore did not experience negative societal attitudes.

#### **4.5.2.4. Program/Policy Barriers**

The most common reported program barrier in the current study was related to human interaction (39%). This included lack of trained volunteers (32%), lack of staff capacity (13%), lack of guidance by staff (5%) and negative attitudes by staff (2%). Other barriers that were mentioned were lack of appropriate programs and accounted for 25% of the total program barriers, lack of adaptive equipment (21%) and cost of programs (14%).

Most of the literature reported similar barriers, namely cost of an exercise program (Scelza, 2005; Malone *et al.* 2012), lack of experience amongst fitness centre staff (Scelza, 2005); lack of adaptive equipment (Crawford and Stodolska, 2008; The Life Group, 2011; Rimmer and Henley, 2013) lack of training of coaches and community based instructors (Johnson, 2008), negative attitudes by health care professionals (Shakespeare and Kleine, 2013) and the qualification of supervision (Jaarsma *et al.*, 2014). Although program or policy barriers were the least reported barriers (13% of the total barriers) it remains important as without appropriate programs or equipment and trained staff PWaSCI cannot partake in safe PA behaviour.

#### **4.5.2.5. Conclusion**

In light of the barriers mentioned above it is evident that PWaSCI face various obstacles in being physically active which ultimately obstructs the road to health and wellness. If health and wellness is not achieved in PWaSCI QOL is affected and it can lead to many other co-morbidities. This demonstrates the importance of identifying and the removal of such barriers to promote and foster an active and healthy lifestyle within this population.

#### **4.5.3. Facilitators**

Although PWaSCI face many barriers to PA, many facilitators were also identified in the study. It is imperative that the identified facilitators be maintained or even enhanced in order to help promote and sustain PA behaviour in this population.

It was not a surprising finding that personal (44%) and social facilitators (26%) played the greatest role in PA participation. These two facilitators involve the human aspect, by either involving the person directly, or their social environment. The personal facilitators included internal motivation such as a desire to be active or to improve self esteem. The social facilitators included the people that surround or provide support to PWaSCI in being

physically active. Although all facilitators are important to consider, without a personal drive to be PA or the necessary family support, a PWaSCI might not even leave the house never mind attend a PA session.

#### **4.5.3.1. Personal Facilitators**

Personal facilitators were reported by 44% of the participants as the main reasons for being physically active. This is important as it determines the person's motivation to be and remain physically active. In this study the most reported personal facilitator was the fact that the people enjoyed exercise and it made them feel good (35%). Second was that they had a desire to be physically active (33%). Some of the participants also said that they are physically active to improve their self confidence. This is consistent with the research done by Stephens *et al.* (2012) and Bailey, Hillman, Arent and Petitpas (2013). Louw *et al.* (2012) identified similar facilitators in the able bodied population and the participants agreed that feeling good motivated them to continue or want to be physically active.

Another facilitator that was identified in this study was to improve general health and strength, which was also found in Louw *et al.* (2012) in the able bodied population. Wu and Williams (2001) found in SCI participants that fun and improving physical fitness and strength to be great motivators, which is consistent with the results found in this study and the study conducted by Kehn and Kroll (2009).

An important facilitator, especially in the SCI community, identified by Kehn and Kroll (2009), was the prevention of secondary conditions. Although it wasn't mentioned in this study under facilitators, the majority of the participants identified and agreed in the research questionnaire that PA helps to prevent secondary conditions. Another facilitator mentioned in Stephens *et al.* (2012) was that the participants felt they had to prove themselves. This is frequently mentioned in the literature as reasons why PWD play competitive sports (Huang and Brittain, 2006; Page, O'Connor and Peterson, 2001). However, it was not found to be a facilitator in this study.

#### **4.5.3.2. Environmental Facilitators**

Environmental facilitators are important especially since they have to do with accessibility. It was the most frequently reported barrier by the participants in this study. For the majority of PWD, including PWaSCI, accessibility is an issue due to decreased/limited mobility. In this study accessible facilities were the most frequently reported facilitator (44%). This is important as people with health disparities associated with a disability such as a SCI have a tendency to live hypoactive lifestyles and yet they have the right to be physically active

(Riley, Riley, Barth B and Rimmer, James H and Wang, Edward and Schiller, William J *et al.*, 2008). Many health disparities that PWD face are not necessarily associated with the disability but instead with the fact that they do not have access to facilities and programs (Rimmer and Rowland, 2008). This exacerbates their disability even more as it affects their health status. This also predisposes PWD to remain in their homes, which may lead to higher levels of sedentary behavior and caloric intake (Rimmer and Rowland, 2008), which ultimately leads to obesity and other secondary conditions, which further exacerbates the barriers they face.

Safe locations (33%) were also an important facilitator identified by the participants. This is understandable, since PWD, including PWaSCI, are vulnerable or easy targets when it comes to crime. This is an important consideration within South Africa due to the high crime rate. In table 29 the crime rate in South Africa is summarized.

**Table 29: Institute for Security Services (ISS) crime hub statistics (2013/2014) South Africa**

<b>Crime South Africa</b>	<b>Rate per 100 people</b>
Murder	32.2
Attempted murder	32.3
Assault with intent to inflict bodily harm	345.7
Robbery with aggravating circumstances	225.3
Common robbery	101.7
Total sexual offenses	118.2

According to NCVRW Resource Guide (2015) and the WHO Department of Violence and Injury Prevention and Disability (2015) PWD are victims of crimes at much higher rates than the rest of the population. It is therefore important that facilities that cater for PWaSCI be in safe and accessible locations. Transport is another facilitator and much less frequently reported since most PWaSCI do not drive, have a vehicle or access to public transport.

#### **4.5.3.3. Social Facilitators**

Family and friend support was a facilitator mentioned by most of the participants in the study. This is consistent with previous literature (Keegan, Chan, Ditchman, and Chiu, 2012; Stephens *et al.*, 2012) and is considered an important facilitator as it leads to increased commitment (Keegan *et al.*, 2012). Another facilitator that is important for PWaSCI to commit to being physically active is support from peers with disabilities (Jaarsma *et al.*, 2014) and

this includes having role models of people who are physically active (Page, O'Connor and Peterson, 2001; Stephens *et al.*, 2012).

Receiving adequate information from rehabilitation and medical staff is also a crucial facilitator as they are the first point of contact after acquiring such an injury. This facilitator accounted for 11% of the social facilitators, indicating that PWaSCI are not receiving adequate information regarding their health and PA opportunities before they are discharged from hospital. Another facilitator that impacts PA behaviour was positive societal attitudes (9%). This low percentage possibly indicates that within South Africa there may still be a stigma associated with PWD, which is consistent with the literature done by Rimmer and Rowland (2008).

#### **4.5.3.4. Program/Policy Facilitators**

Most of the facilitators identified under program/policy section were related to people being available and competent to assist (skilled staff 20%; enough staff 16%; enough trained volunteers 13%). The last facilitator mentioned was the availability of more and better quality programs (20%). Having sufficient and skilled staff is important as some PWaSCI need assistance with wheelchair transfers, stretching and guidance by exercise staff in order to execute the exercises correctly. Not many studies reported on program/policy facilitators, however, The Life Group study (2011) identified that individual tailored programs, a facility that supports people with similar conditions and disabilities and an exercise program that considers individual motivators. Although very few researchers reported on this facilitator it is important as without trained staff and appropriate programs PWaSCI will not be able to partake in safe and healthy behaviour such as PA.

#### **4.5.3.5. Conclusion**

Facilitators are the crucial ingredient to introduce and sustain PA. We therefore urge the government to help with this endeavor in creating a healthier nation by making facilities available that are accessible, fitted with the right adaptive equipment and trained staff to assist PWaSCI with PA. It is clear from the facilitators that PWaSCI are eager to be physically active, however, the environment and lack of accessible and appropriate programs pose a big obstacle in achieving this.

## CHAPTER 5

### RESULTS AND DISCUSSION: PHASE II

#### 5.1. Introduction

In this chapter, the results of phase II of the study are presented and discussed. This includes both quantitative and qualitative data of the intervention phase. The results are presented according to the aims and objectives of the study. There are two main parts to this phase. The first part was to develop a PA program targeting the barriers identified in Phase I of the study and secondly, to determine whether the participants would adhere to the PA program and, ultimately, post-intervention improvement in community reintegration. The objective for the first part was:

**Objective 1:** To compare the impact of a general exercise program in a formal and community based setting on the physical abilities (cardiovascular endurance, strength, functional ability (RNLI)) of the participants at pre-, two and four months post-intervention.

The objectives of the second part of phase II included the determination of the impact of a physical activity program on exercise adherence in the SCI population. Thus:

**Objective 2:** To compare the perceived barriers pre and post-intervention for the different training environments.

The chapter begins with the socio-demographic and injury profile of the participants who participated in the intervention and will lead into the objectives.

#### 5.2. Socio-Demographic and Injury Profile of the Participants

The participants were purposefully selected and had to meet the inclusion criteria stipulated in the methods section of this study. A total of 23 participants agreed to participate in the study. However, three of the selected participants did not meet the inclusion criteria. One participant was excluded, because he was classified as high risk according to the PARQ and YOU questionnaire and he was unable to obtain a clearance letter from the doctor. The other two participants were excluded from the study, because they could not manually propel their wheelchairs.



The data in table 30 represents the participants who completed the intervention successfully and does not include the participants who dropped out during the intervention. A total of four participants dropped out during the intervention and their reasons are presented in table 31. As indicated in table 30, a total of 16 participants completed the study without injury or any additional medical complications. Fifteen of the participants were male and one participant was female. The average age of the participants was 40, with the youngest participant being 19, and the oldest, 53 years of age. The participants from the Community group were on average 10 years older than the participants from the WCRC group. In this phase of the study, the majority (81%) of the participants were Coloured. Only 19% of the participants were Black. The majority of the participants were paraplegics (ratio 1.3:1) and only two had incomplete lesions.

**Table 30: Participant socio-demographic and injury profile**

Participant Profile			WCRC Group	Community Group
	n = 16	%	n = 8	n = 8
<b>GENDER</b>				
Male	15	94	8	7
Female	1	6	0	1
<b>AGE</b>				
Mean	40	/	34	43
Range	19-53	/	19-51	27-53
<b>ETHNICITY</b>				
Black	3	19	3	0
Coloured	13	81	5	8
White	0	0	0	0
Indian/Asian	0	0	0	0
<b>TYPE OF INJURY</b>				
Tetraplegic	5	31	2	3
Paraplegic	11	69	6	5
<b>INJURY LEVEL</b>				
C4-C8	7	44		
T1-T4	3	19		
T5-T12	6	37		

**Table 31: Reasons for participant drop-out from the PA program**

Group	Number (n)	Drop out	Reasons
<b>1</b> <b>WCRC</b>	10	2	One participant stopped attending sessions for unknown reasons* One participant had to stop because he broke his femur and was hospitalised for the remainder of the intervention*
<b>2</b> <b>Strand</b>  <b>Macassar</b>	10	2	One participant died due to a bladder infection just prior to the start of the intervention One participant withdrew after completing a few sessions due to pressure sores*

**Table 32: Participant adherence rate to the PA program**

Adherence rate (sessions missed)	WCRC Group n = 8	Community Group n = 8
<b>1</b>	0	1
<b>2 random</b>	1	3
<b>3 random</b>	1	1
<b>4 random</b>	0	1
<b>5 random</b>	1	1
<b>4 consecutive</b>	2*	1*
<b>6 sporadic</b>	0	0

Table 31 summarises the reasons for the participants leaving the PA program and table 32 shows the amount of sessions that were missed in each group during the initial eight week intervention. The table indicates that three participants, one from the Community group and two from the WCRC group left the PA program, because of missing four consecutive sessions (according to the exclusion criteria stipulated in chapter 3). The reasons for the two participants missing four consecutive sessions are described in table 31 (\*).

In the next section of this chapter, the results of the physical tests, mRNLi and the research questionnaire are presented and discussed.

### **5.3. Results: Impact of Physical Activity on Physical Abilities and mRNLI Over Time**

In order to answer research objective one (section 5.1.) four different measurements were taken to determine the physical abilities of the participants. The first measurement, the manual muscle test (MMT), was used to test the strength of the intact muscle groups (functional movement of shoulder, elbow and wrist). Two of the measurements assessed functional mobility as well as functional power and flexibility (one-stroke-push-task and forward-vertical-reach-test, respectively). The fourth measurement (12-min-push-test) measured cardiovascular endurance. The RNLI was used to assess each participant's satisfaction with community participation. These results are summarised in table 33.

#### **5.3.1. Modified Return to Normal Living Index (mRNLI)**

Pre-intervention the Community group started with 19.1 points and the WCRC group with 24.3 points out of a total of 33 points for the mRNLI. The only significant difference between the two groups was found at two months post-intervention ( $p < 0.05$ ).

Both groups showed improvement over time, especially, at four months post-intervention. There was a significant difference found in the WCRC group at both two and four months post-intervention-intervention in comparison with the baseline measurements ( $p < 0.05$ ). In the Community group, the only significant difference was found at four months post-intervention in relation to the baselines measurement ( $p < 0.05$ ).

The percentage change, illustrated in figure 13, shows a greater increase in the Community group from the baseline measurements, especially, at four months post-intervention. The increase from baseline was 35.1%. At four months post-intervention, the WCRC group only showed a 15.2% change from baseline.

**Table 33: mRNLI Index at baseline and post-intervention in the Community and WCRC groups (VAS 4 point ordinal scale)**

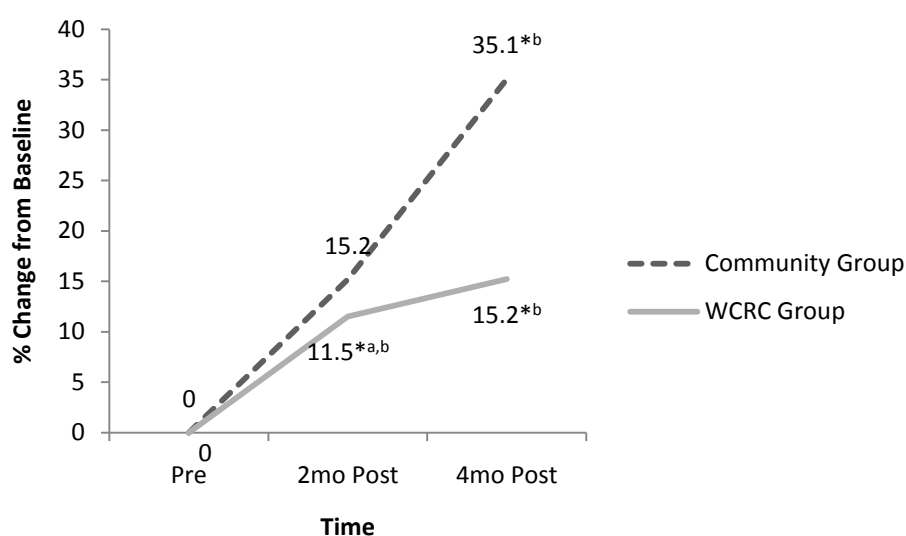
Tests	Group	Pre	95% CI	2mo		4mo	
				Post	95% CI	Post	95% CI
mRNLI	Community	19.1	(13.3-25.0)	22.0	(17.1-26.9)	25.8 <sup>b</sup>	(20.5-31.0)
	WCRC	24.3	(21.9-26.6)	27.1 <sup>a,b</sup>	(25.3-29.0)	28.0 <sup>b</sup>	(26.0-30.0)

CI = confidence interval

<sup>a</sup>  $p \leq 0.05$  between the WCRC group and the Community group.

<sup>b</sup>  $p \leq 0.05$  between the post-intervention measures (2m post-intervention or 4m post-intervention) and the pre-intervention measure.

Number of participants in each group = 8



\* $p < 0.05$

<sup>a</sup>  $p \leq 0.05$  between the WCRC group and the Community group.

<sup>b</sup>  $p \leq 0.05$  between the post-intervention measures (2m post-intervention or 4m post-intervention) and the pre-intervention measure.

**Figure 13: Percentage change in mRNLI in the Community and WCRC group from baseline over time**

### 5.3.2. Manual Muscle Test (MMT)

Concentric muscle testing was conducted of different functional movements in the shoulder, elbow and wrist and is summarised in table 34. Each muscle group was divided into the right and left side. The majority of the participants were right hand dominant ( $n=12$ ). At baseline (pre-intervention testing) significant differences were found between the two groups in the left wrist ( $p < 0.05$ ) and at two months, in the left shoulder, left elbow and left wrist ( $p < 0.05$ ).

At four months post-intervention-testing significant differences were found between the two groups in both the left and right upper extremities (shoulder, elbow and wrist) ( $p < 0.05$ ).

Although both groups increased in strength, more significant results were found in the WCRC group over time. In the WCRC group, significant differences were observed at four months from baseline in all the muscle groups, except for the left and right wrist ( $p < 0.05$ ). In the Community group, the only significant difference from baseline, was found in the right shoulder and wrist ( $p < 0.05$ ).

The percentage change, over time shows that the WCRC group underwent a greater change, over time from their respective baselines measurements (Fig. 14). Most of the increases in muscle strength that took place were similar, except for the right arm in the WCRC group, which was considerably higher than the rest (47.5%).

**Table 34: Manual muscle test results (Grade 0-5)**

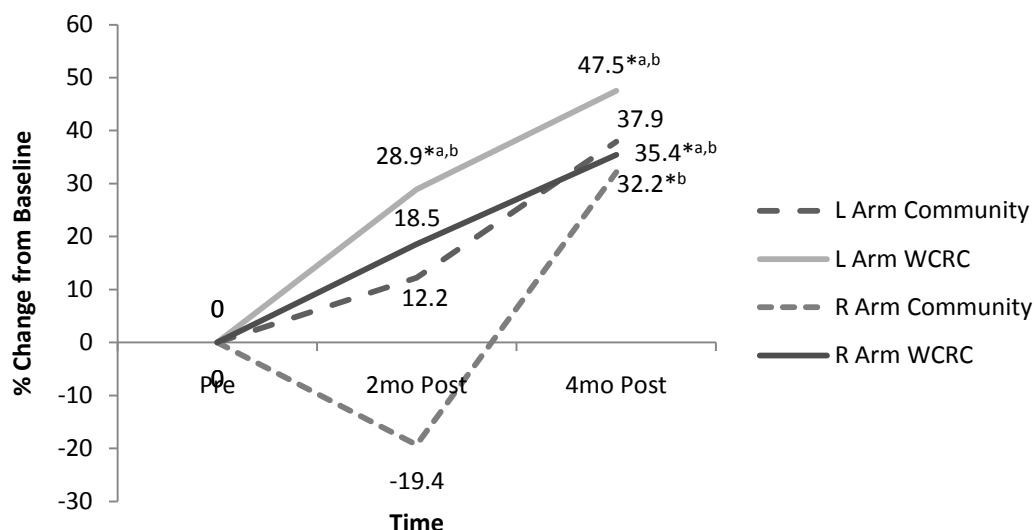
Tests	Group	Pre	95% CI	2mo		4mo	
				Post	95% CI	Post	95% CI
<b>L shoulder MMT</b>	Community	20.8	(16.6-24.9)	20.6	(16.4-24.8)	23.3	(22.4-24.1)
	WCRC	23.9	(21.7-26.1)	25.9 <sup>a</sup>	(25.1-26.6)	27.6 <sup>a,b</sup>	(26.8-28.5)
<b>R shoulder MMT</b>	Community	21.6	(18.5-24.7)	20.5	(14.9-26.1)	24.8 <sup>b</sup>	(23.2-26.3)
	WCRC	24.5	(22.3-16/7)	25.9	(25.0-26.8)	27.5 <sup>a,b</sup>	(26.2-28.8)
<b>L elbow MMT</b>	Community	6.6	(5.0-8.3)	6.9	(5.7-8.1)	7.4	(6.9-7.8)
	WCRC	7.8	(7.0-8.5)	8.8 <sup>a,b</sup>	(8.3-9.2)	9.3 <sup>a,b</sup>	(8.6-9.9)
<b>R elbow MMT</b>	Community	7.4	(5.9-8.8)	6.8	(4.7-8.8)	8.0	(7.7-8.3)
	WCRC	8.0	(7.1-8.9)	8.6	(8.1-9.1)	9.0 <sup>a,b</sup>	(8.4-9.6)
<b>L wrist MMT</b>	Community	5.8	(3.7-7.8)	6.3	(4.7-7.8)	6.6	(6.1-7.2)
	WCRC	7.8 <sup>a</sup>	(6.5-9.0)	8.4 <sup>a</sup>	(7.8-9.0)	8.8 <sup>a</sup>	(8.1-9.4)
<b>R wrist MMT</b>	Community	6.5	(4.4-8.6)	6.1	(4.0-8.2)	7.1 <sup>b</sup>	(6.4-7.8)
	WCRC	7.5	(5.8-9.2)	7.9	(7.4-8.4)	8.3 <sup>a</sup>	(7.7-8.8)

CI = confidence interval

<sup>a</sup>  $p \leq 0.05$  between the WCRC group and the Community group.

<sup>b</sup>  $p \leq 0.05$  between the post-intervention measures (2m post-intervention or 4m post-intervention) and the pre-intervention measure.

Number of participants in each group = 8



\* $p < 0.05$

<sup>a</sup>  $p \leq 0.05$  between the WCRC group and the Community group.

<sup>b</sup>  $p \leq 0.05$  between the post-intervention measures (2m post-intervention or 4m post-intervention) and the pre-intervention measure.

**Figure 14: Percentage change in MMT in the Community and WCRC groups from baseline over time**

### 5.3.3. 12-min-Push Test (12min PT)

In table 35 the Community group's average at pre-intervention was 187.6m (CI = -47.7-422.8) in comparison with the WCRC groups of 672.6m (CI = 460.5-884.8). Over all three time points the WCRC group was able to push statistically significantly greater distances than the Community group. However, at four months post-intervention the Community group showed the only significant increase from baseline over time ( $p < 0.05$ ).

The Community group showed a 48.9% increase at two months and a 138.1% increase at four months from baseline (Fig. 15). This percentage change was much higher than the 2.3% and the 9.7% change that took place in the WCRC group (at two months and four months post-intervention, respectively).

**Table 35: 12-min-push test results (m)**

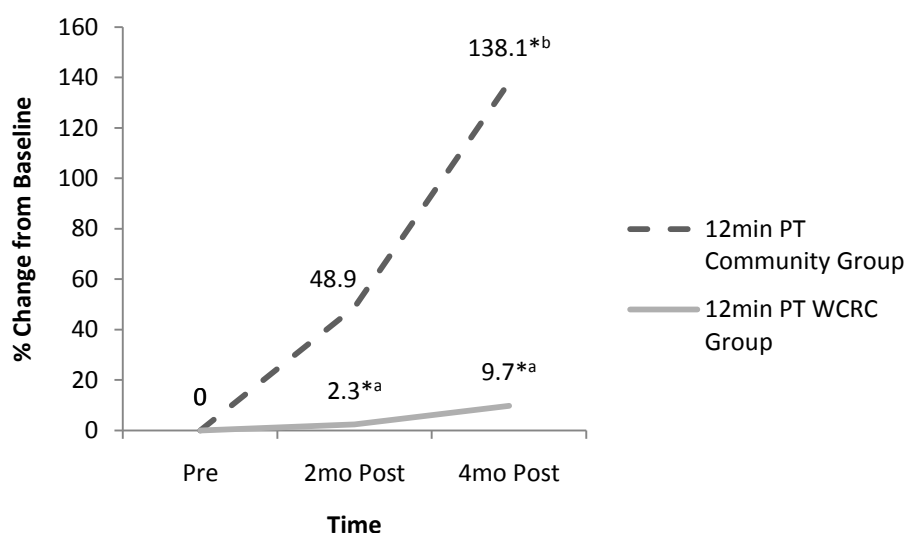
Tests	Group	Pre	95% CI	2mo		4mo	
				Post	95% CI	Post	95% CI
12min PT	Community	187.6	(-47.7-422.8)	279.3	(210.4-348.2)	446.7 <sup>b</sup>	(297.5-596.0)
	WCRC	672.6 <sup>a</sup>	(460.5-884.8)	688.3 <sup>a</sup>	(586.1-790.5)	737.7 <sup>a</sup>	(673.7-801.7)

CI = confidence interval

<sup>a</sup>  $p \leq 0.05$  between the WCRC group and the Community group.

<sup>b</sup>  $p \leq 0.05$  between the post-intervention measures (2m post-intervention or 4m post-intervention) and the pre-intervention measure.

Number of participants in each group = 8



\* $p < 0.05$

<sup>a</sup>  $p \leq 0.05$  between the WCRC group and the Community group.

<sup>b</sup>  $p \leq 0.05$  between the post-intervention measures (2m post-intervention or 4m post-intervention) and the pre-intervention measure.

**Figure 15: Percentage change in 12min-push-test in the Community and WCRC group from baseline over time**

#### 5.3.4. One-Stroke-Push Task (1 stroke PT)

The WCRC group performed statistically significantly better at baseline and post-intervention than the Community group ( $p < 0.05$ ). The performance of the Community group declined at four months post-intervention ( $p > 0.05$ ). Although a significant difference was observed between the groups, both groups improved over time, although the improvement was not significant in either of the groups ( $p > 0.05$ ) as seen in table 36.

There was an initial increase of 19.3% from baseline at two months post-intervention in the Community group, however, at four months, this percentage increase was reduced to 9.5% from baseline (Fig. 16). Although a decrease was observed, the value remained higher than the pre-intervention value.

**Table 36: One-Stroke-Push Task Results (cm)**

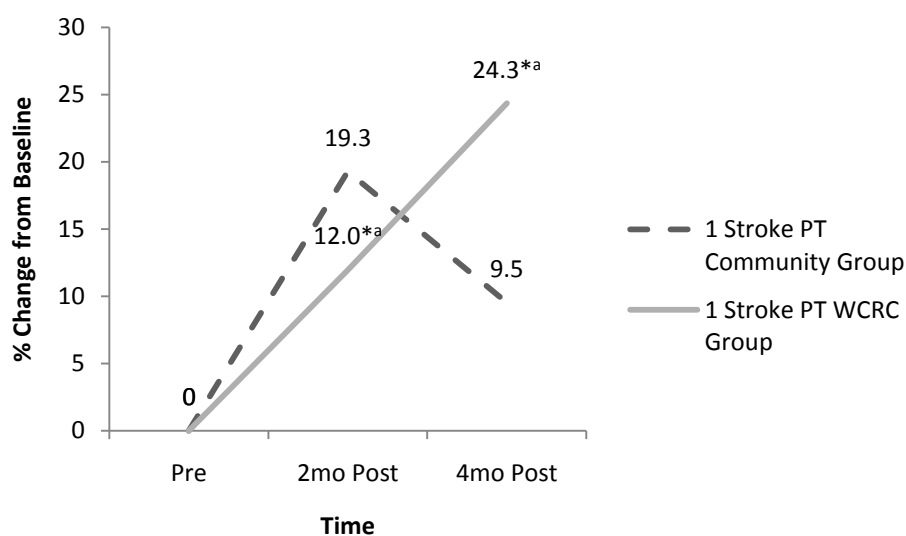
Tests	Group	Pre	95% CI	2mo		4mo	
				Post	95% CI	Post	95% CI
1 Stroke PT	Community	239.8	(32.0-447.6)	286.0	(251.3-320.7)	262.6	(217.1-308.2)
	WCRC	471.1 <sup>a</sup>	(291.5-650.6)	527.4 <sup>a</sup>	(482.0-572.7)	585.8 <sup>a</sup>	(521.3-650.2)

CI = confidence interval

<sup>a</sup>  $p \leq 0.05$  between the WCRC group and the Community group.

<sup>b</sup>  $p \leq 0.05$  between the post-intervention measures (2m post-intervention or 4m post-intervention) and the pre-intervention measure.

Number of participants in each group = 8



\* $p < 0.05$

<sup>a</sup>  $p \leq 0.05$  between the WCRC group and the Community group.

<sup>b</sup>  $p \leq 0.05$  between the post-intervention measures (2m post-intervention or 4m post-intervention) and the pre-intervention measure.

**Figure 16: Percentage change in the one-stroke-push task in the Community and WCRC group from baseline over time**



### 5.3.5. Forward-Vertical-Reach Test (Fwd VRT)

During the forward-vertical-reach test the Community group tested very similar to the WCRC and no significant differences were found between the two groups ( $p>0.05$ ). Both groups improved over time, however, the only significant improvement was observed in the WCRC group at four months post-intervention ( $p<0.05$ ).

In figure 17 it is shown that the percentage change that took place in this test was much lower in comparison with the other tests. In the WCRC group the major improvement may be observed in the difference between two and four months post-intervention from baseline (3.9% and 5.7% change, respectively).

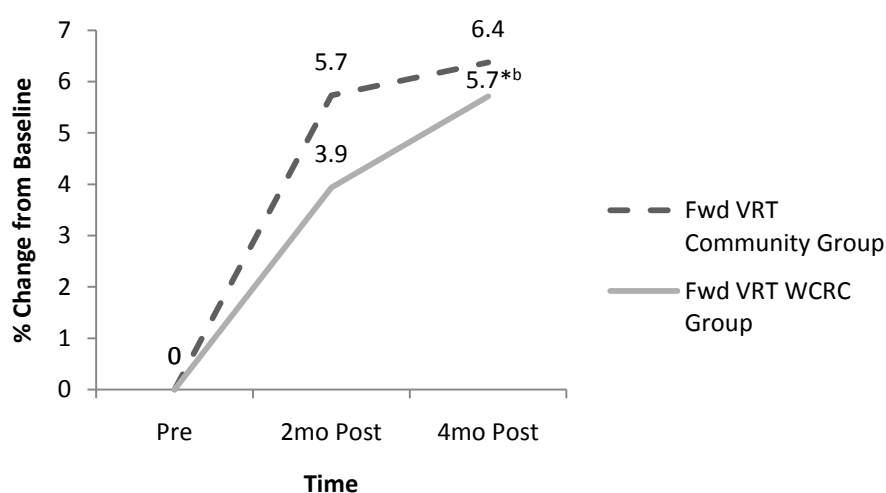
**Table 37: Forward-vertical-reach test results (cm)**

Tests	Group	Pre	95% CI	2mo		4mo	
				Post	95% CI	Post	95% CI
Fwd RT	Community	155.3	(144.4-166.3)	164.2	(153.9-174.5)	165.2	(155.9-174.6)
	WCRC	157.6	(151.1-164.1)	163.8	(161.1-166.6)	166.6 <sup>b</sup>	(163.0-170.2)

CI = confidence interval

<sup>a</sup>  $p\leq 0.05$  between the WCRC group and the Community group.

<sup>b</sup>  $p\leq 0.05$  between the post-intervention measures (2m post-intervention or 4m post-intervention) and the pre-intervention measure.



\* $p<0.05$

<sup>a</sup>  $p\leq 0.05$  between the WCRC group and the Community group.

<sup>b</sup>  $p\leq 0.05$  between the post-intervention measures (2m post-intervention or 4m post-intervention) and the pre-intervention measure.

**Figure 17: Forward-vertical-reach test % change from baseline**

## **5.4. Discussion: Impact of Physical Activity Program on Physical Abilities and mRNLI Over Time**

The purpose of the intervention was to demonstrate that a community based physical activity group is able to achieve similar results to that of a group in a formal exercise setting/environment. Although very few significant differences were found between the groups, pre-intervention (12 min-push test and one-stroke-push test), at two and four months post more significant differences were observed between the two groups. Both groups also showed to improve significantly over time. The improvement over time was expected and was particularly evident at four months post-intervention.

In general, the WCRC group had higher values in terms of upper limb strength (MMT), functional power (one-stroke-push task), and flexibility (forward-vertical-reach test) and in the cardiovascular test (12 min-push test) at pre-intervention, two and four months post-intervention. It should be noted that the participants of the WCRC group were stronger, more flexible and their cardiovascular fitness with higher initial values to start with and the group was more homogenous than the Community group (heterogeneous group) in terms of performance. The rest of the results discussed below indicate that it is possible for a community based PA group to improve their physical abilities by following a twice weekly exercise program for 16 weeks.

### **5.4.1. Modified Reintegration to Normal Living Index**

The mRNLI was used to measure the participants' satisfaction with their community participation. The statistically significant results in this study show that over a four month period, PWaSCI can achieve greater satisfaction with their community reintegration. This indicates that PWaSCI who follow a structured PA program twice a week could improve with regards to their daily functioning and also in their self-perception. These results indicate that a PA program can be helpful to foster community participation within PWaSCI.

Although the WCRC group scored higher at all three time points, both groups improved over time. This could possibly be explained by the improvement in the physical abilities that the participants from both groups experienced during the intervention. In general, greater improvements were observed at four months post-intervention. The only significant difference that was found between the two groups was at two months post-intervention. A possible explanation for this could be that the Community group took longer to significantly improve in the other tests and this possibly affected their perception. Another possible explanation could be that although the barriers to PA were reduced, the barriers within their

communities continued to pose a restriction on community participation. Although both groups improved over time, it took the Community group longer to improve significantly. This may also be explained by the Community group's injury profile in that some of the participants had higher lesions. In addition, this also impacts a PWaSCI independence, which also affects community reintegration.

#### 5.4.2. **Manual Muscle Test**

The purpose of the MMT was to assess if the PA program was successful in increasing the strength of the participants. MMT has been recommended by the American Spinal Injury Association as an accurate means to assess strength (Herbison *et al.*, 1996).

The PA program was successful in increasing strength in both groups, as indicated by the increase in the percentage change from baseline. Significant differences were found between the two groups at two and four months post-intervention and could possibly be explained by individual differences such as residual muscle function, dominance and lesion level. The higher injury levels that were present in the Community group could explain why less improvement in performance took place, especially at two months post-intervention. PWaSCI, who have a higher lesion level, generally have fewer intact muscles or innervated fibres that are able to increase in strength and diameter through PA. It may also take longer for these muscles to significantly increase in strength, which is supported by the results found at four months post-intervention.

Within the Community group, significant improvements took longer and were only visible at four months post-intervention. The longer the participants were exposed to PA, the greater the improvements in strength became evident. According to Gordon and Mao (1994) and Kelley, Nim, Rousseau, Fowles and Murphy (2006), muscles that lose their innervations undergo muscle wasting and therefore a significant decrease in muscle mass takes place. Prevention of further atrophy is dependent on the capacity of the nerves that survive denervation to sprout and innervate as many denervated muscle fibres as possible (Gordon and Mao, 1994). In certain tetraplegics wrist function is also non-existent and therefore no improvements can be made. This explains the significant difference between the two groups in the left wrist. This was illustrated at all three time points, with a significant difference between the groups in the left wrist ( $p < 0.05$ ) and no significant improvement in the Community group. This is also supported by the fact that the Community group was more heterogeneous and improvements took place in participants at different time points due to their lesion levels.

Although not all the improvements were significant, neither of the groups showed a significant decrease in any of the MMT measurements. This was expected since strength training was part of the PA program and the intensity of the exercises was also increased every week. Weight or strength training can be used successfully to increase strength and help deter the effects of the injury in PWaSCI (Jacobs and Nash, 2004).

The results of this study show that increases in strength can be achieved by participation in a PA program, twice a week, for eight consecutive weeks. However, greater and more significant improvements were observed after 16 weeks. Similar results were found by Hicks and McCartney (2003) who found improvements in strength after implementing a PA program twice a week, for nine months. Although their program's duration was nine months in total, significant improvements were already observed after three months.

Based on the information above one may be tempted to speculate that there may be a correlation between the mRNLI and improvements in strength. This correlation is because muscle strength improvements have the capacity to assist with the ability to complete ADL (Hicks *et al.*, 2011; Hicks and McCartney, 2003)

#### 5.4.3. **12 min-Push Test**

The 12 min-push test was modified from the original version in order to accommodate for environments where a 400m track was not available. According to Vanderthommen *et al.* (2002) a distance above 2560m is excellent and a distance below 1010m is poor. In the current study a figure eight was used with a total lap distance of 48m, which resulted in more turning, which possibly took up more time and increased fatigue in the wheelchair user. Vanderthommen *et al.* (2002) normative data can therefore not be used to accurately interpret the cardiorespiratory fitness levels of the participants in this study.

The Community group showed the only significant increase over time from baseline to four months post-intervention (138.1%) ( $p < 0.05$ ). The WCRC group did not show significant improvements over time (10%) ( $p > 0.05$ ). There was, however, a significant difference between the two groups at all the testing points, with the WCRC group achieving greater distances ( $p < 0.05$ ). A possible reason for the non-significant improvement in the WCRC group over time could be ascribed to the fact that these participants already had a higher fitness level and therefore improvements were more difficult to achieve. Another possible reason for the small increase was that the 10-20 minutes of cardiovascular exercise in the program was not enough to increase the cardiovascular fitness in these participants. However, within the Community group, the 'opposite' observation was made, as their

performance improved significantly from baseline to four months post-intervention. This possibly suggests that for PWaSCI who have a low cardiovascular fitness level, completing 10-20 minutes of cardiovascular exercise, twice a week, for 16 consecutive weeks is enough to see a significant improvement. However, in PWaSCI who have a higher fitness level, this training load may not be sufficient to see significant improvements. This is supported by Hicks *et al.* (2011) who stated that maximal power output achieved during maximal exercise tests is an indirect indicator of muscle strength and that peak power output can be improved following 16 weeks of training that incorporates strength, aerobic and mobility exercises.

#### 5.4.4. One-Stroke-Push Task

The one-stroke-push task was used to assess functional power in an everyday common task. PWaSCI have to continuously use power to push onto different surfaces such as carpets or sand within their communities and homes. From the first measurement to the last measurement there was a significant difference between the groups ( $p < 0.05$ ). This can possibly be explained by the higher lesion levels of the Community group. The participants in the WCRC group were also stronger to start with, which was also illustrated through the MMT.

In the WCRC group there was continuous improvement over the four month period, although not significant ( $p > 0.05$ ). In the Community group, there was an increase in performance at two months, but a decrease at four months. It was expected that both groups would increase in the distance that they pushed as they improved their strength.

There are many factors that influence the ability of a PWaSCI to execute this task. These factors include seating (positioning of the person in his/her wheelchair), muscle strength, wheelchair mechanics, and body mass of the person as well as the weight of the wheelchair. In the Community group, it was more difficult to ensure proper wheelchair mechanics without the necessary support services. Also at four months it was winter and consequently a lower attendance rate was observed within the Community group at the exercise sessions. The cold weather also impacted the movement ability of the participants and they struggled to use their manual wheelchairs. In the WCRC group the tests were performed in a thermally stable environment, as the facility had a heater. During winter, the participants from the Community with the higher lesion levels also did not use their manual wheelchairs very often, thus decreasing the use of their muscles and skills on a daily basis. This possibly explains why there were no significant improvements within the groups over time and probably accounts for the decreased performance that occurred in the Community group at four months post-intervention.

Although the Community group's distance decreased at four months post-intervention, it was still higher than the baseline measurement. It is possible to suggest that, because of all the environmental factors that influence this action, it is not a suitable test for power although functional mobility could be tested. Because of all the external influences it is also possible that an increase in muscle strength does not necessarily ensure an increase in power (distance pushed) if all the other factors are not accounted for. Hence, the strength training program and functional exercises in this study were not sufficient to significantly increase functional power as measured in this test.

#### 5.4.5. **Forward-Vertical-Reach Test**

The forward-vertical-reach test is a functional task measuring both flexibility and the ability to lift the upper limbs to complete tasks necessary for daily living, such as reaching for an object. Flexibility is important and necessary for completing ADL (President's Council on Physical Fitness and Sports, 2008) and together with strength training, can prevent shoulder pain (Nawoczinski and Ludewig, 2006; van Drongelen *et al.*, 2006).

In this test, no significant differences were observed between the two groups at all three time points and both groups showed greatest improvements at two months post-intervention. The only significant increase was found in the WCRC group at four months post-intervention in comparison with the baseline measurement ( $p < 0.05$ ). A possible explanation for the non-significant improvement over time in the Community group could be that it was more difficult for the participants to complete the test. Within the Community group more participants had less trunk control due to the higher lesions and therefore demonstrated less stability. This also affected the ability of the participants to lift their arms without losing their balance.

#### 5.4.6. **Conclusion**

The main aim of the study was to see whether a PA program was successful in improving the physical abilities of PWaSCI within a formal (WCRC) and a community based environment. The program was shown to be successful as all the participants improved in the majority of the tests as well as in the mRNLI. This was particularly evident in the percentage change that took place over time within the Community group. This suggests that a PA program within a community with basic equipment and trained volunteers can significantly improve strength, flexibility and cardiovascular endurance in the participants. This was important as all of these aspects contribute to improved QOL and health by reducing the occurrence of secondary conditions and possible hospitalisation.

The next section examines the barriers and the facilitators that were targeted in the PA program. The aim was to determine whether reduced barriers would lead to continued PA participation within the different environments.

## **5.5. Results: Change in Barriers and Facilitators over Time**

The results in phase II of the study revealed that the participants identified many barriers and facilitators to PA participation. These were grouped into four different categories and are presented in table 36. The importance of this part of the research is to note the change in barriers and facilitators over time. Prior to the intervention the research questionnaire identified certain barriers that prevented PWaSCI from being physically active (Chapter 4). During the intervention, these barriers identified in phase I of the study were targeted and removed where possible and is further discussed in section 5.6. The results in this section demonstrate whether the program was successful in removing the barriers and whether certain barriers were influenced by external factors out of the researcher's control.

The most common barriers that were identified prior to the intervention included: lack of finances, lack of skill and knowledge, lack of facilities, lack of transport, lack of information lack of appropriate programs and equipment, and lack of trained volunteers. In table 38 the changes in the number of barriers and facilitators are summarised as the percentage change that took place during the course of the intervention.

At six months post-intervention when the final research questionnaire was administered, the total barriers were reduced from 39 to 14 in the WCRC group indicating a 64% reduction and from 74 to 18 in the Community group, indicating a 76% reduction ( $p < 0.05$ ). It was expected that the facilitators would increase or remain the same, however, the facilitators initially identified were also reduced at six months post-intervention, although not statistically significant ( $p > 0.05$ ). This number was reduced by 15% in the WCRC group and by 26% in the Community group. As shown in table 36 the Community group underwent a greater change in both reducing the barriers, but also the facilitators, compared to the WCRC group. Possible reasons and explanations for changes are discussed in section 5.6 and 5.7.

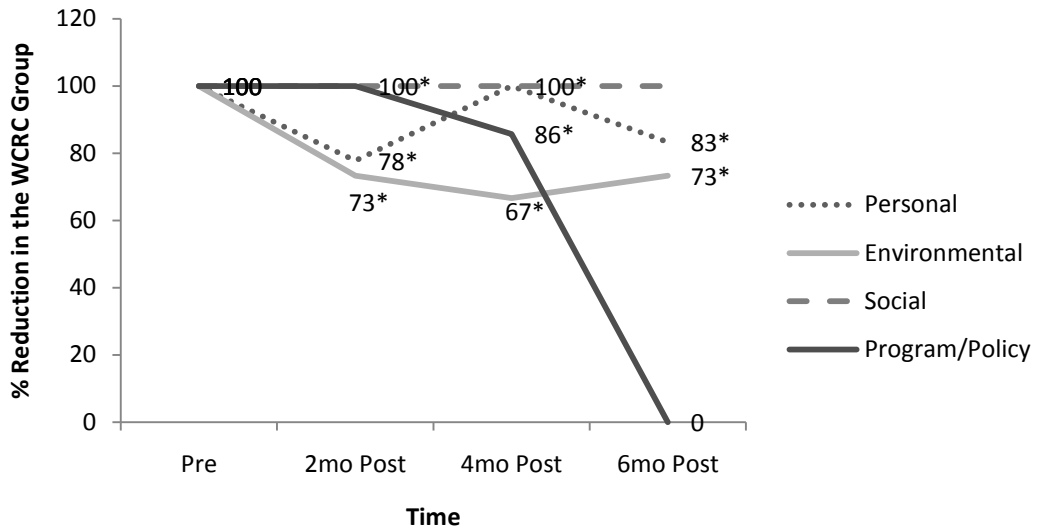
**Table 38: Percentage change in the number of barriers and facilitators as reported by the participants at pre-intervention and two and six months post-intervention**

WCRC Barriers			Community Barriers		
Pre (n)	2mo Post (n) (% change)	6mo Post (n) (% change)	Pre (n)	2mo Post (n) (% change)	6mo Post (n) (% change)
39	7 (82)	14 (64)	74	2 (97)	18 (76)
WCRC Facilitators			Community Facilitators		
Pre (n)	2mo Post (n) (% change)	6mo Post (n) (% change)	Pre (n)	2mo Post (n) (% change)	6mo Post (n) (% change)
46	39 (15)	39 (15)	39	37 (5)	29 (26)

### 5.5.1. Barriers Reported by the Participants

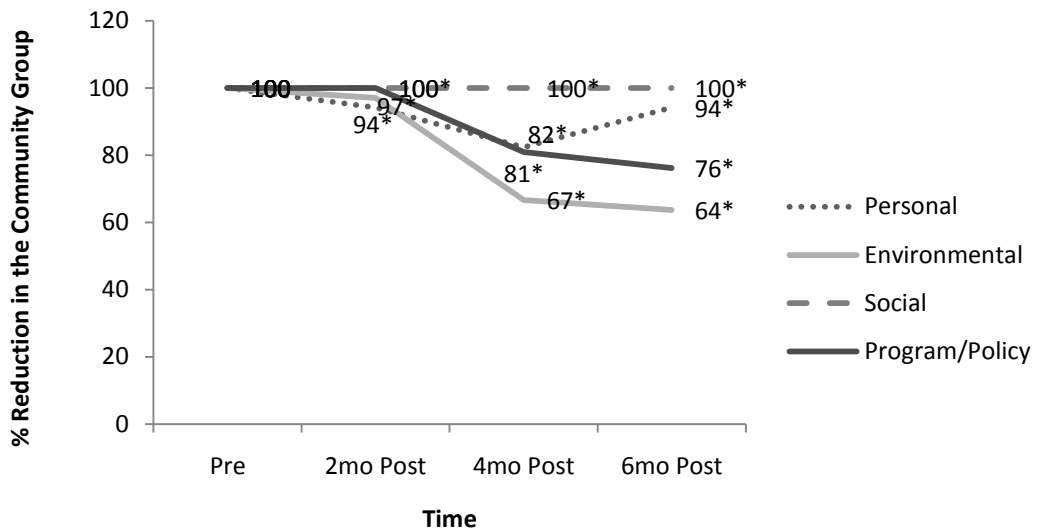
Prior to and during the intervention, the participants reported a large number of barriers to PA. In the graphs on the following page the barriers are presented and compared over four different time points (pre-intervention, two, four and six months post-intervention). The majority of the barriers that were identified were reported by the participants from the Community group. Most of these were environmental barriers (43%), and 49% of the reported barriers were lack of transport. The least reported were the social barriers (7%), with nine percent of the participants indicating that lack of information received about being physically active was their main barrier to PA.





\*p<0.05

**Figure 18: Reduction in the number of barriers (%) in the WCRC group from baseline over time**



\*p<0.05

**Figure 19: Reduction in the number of barriers (%) in the Community group from baseline over time**

### 5.5.2. Personal Barriers

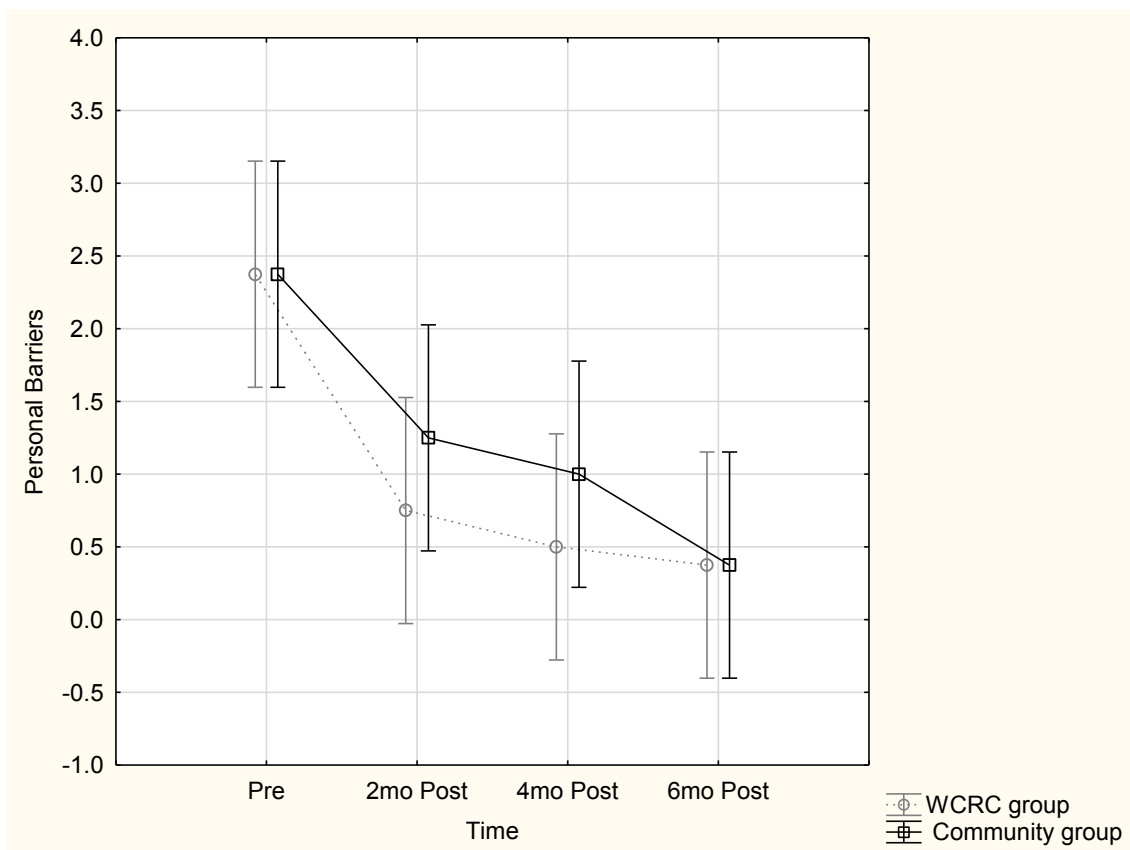
Prior to the start of the intervention, both groups reported approximately the same number of barriers, namely WCRC 18 barriers and Community group 17. The barriers reported were also very similar and there was no significant difference found between the groups over time (p>0.05). Although no significant differences were found between the two groups, significant

differences were observed within the groups over time ( $p < 0.05$ ). The most reported personal barrier for both groups was injury level (75%). Lack of finances was the second most reported barrier in the WCRC group (50%) while lack of skill was the most reported barrier in the Community group (50%). Lack of knowledge about being physically active was the third most reported barrier (37.5% participants in each group). Secondary complications accounted for 37.5% in both groups and 12.5% of participants from WCRC said that lack of time to exercise was a barrier. In general, there was not a significant difference observed between the two groups in the number of barriers and type of barriers that were identified.

The barriers faced by both groups were considerably reduced after the initial eight week intervention. Personal barriers for the WCRC group were reduced from 16 to three indicating an 81% reduction and in the Community group from 15 to one, showing a 93% decrease ( $p < 0.05$ ). The participants, who indicated that their injury level was a barrier, were reduced from 75% to 25%. The only barriers that remained in both groups were secondary conditions (12.5% in the Community and 25% in the WCRC group). At six months post-intervention 37.5% of the participants said that secondary conditions remained a problem in the WCRC group and one other barrier was identified by 12.5% of the participants in the Community group. The other barrier was employment.

**Table 39: Change in personal barriers over time for the different environments**

Barriers	WCRC Group				Community Group			
	% (n)				% (n)			
Personal	Pre	2mo	4mo	6mo	Pre	2mo	4mo	6mo
Injury level	75 (6)	25 (2)	0	0	75 (6)	0	0	0
Secondary Conditions	37.5 (3)	25 (2)	0	37.5 (3)	37.5 (3)	12.5 (1)	37.5 (3)	0
Lack of finances	50 (4)	0	0	0	12.5 (1)	0	0	0
Lack of skill	12.5 (1)	0	0	0	50 (4)	0	0	0
Lack of knowledge	37.5 (3)	0	0	0	37.5 (3)	0	0	0
Lack of time	12.5 (1)	0	0	0	0	0	0	0
Other	0	0	0	0	0	0	0	12.5 (1)



$p > 0.05$  (group\*time effect)

**Figure 20: The change in the total barriers over time between the two groups**

### 5.5.3. Environmental Barriers

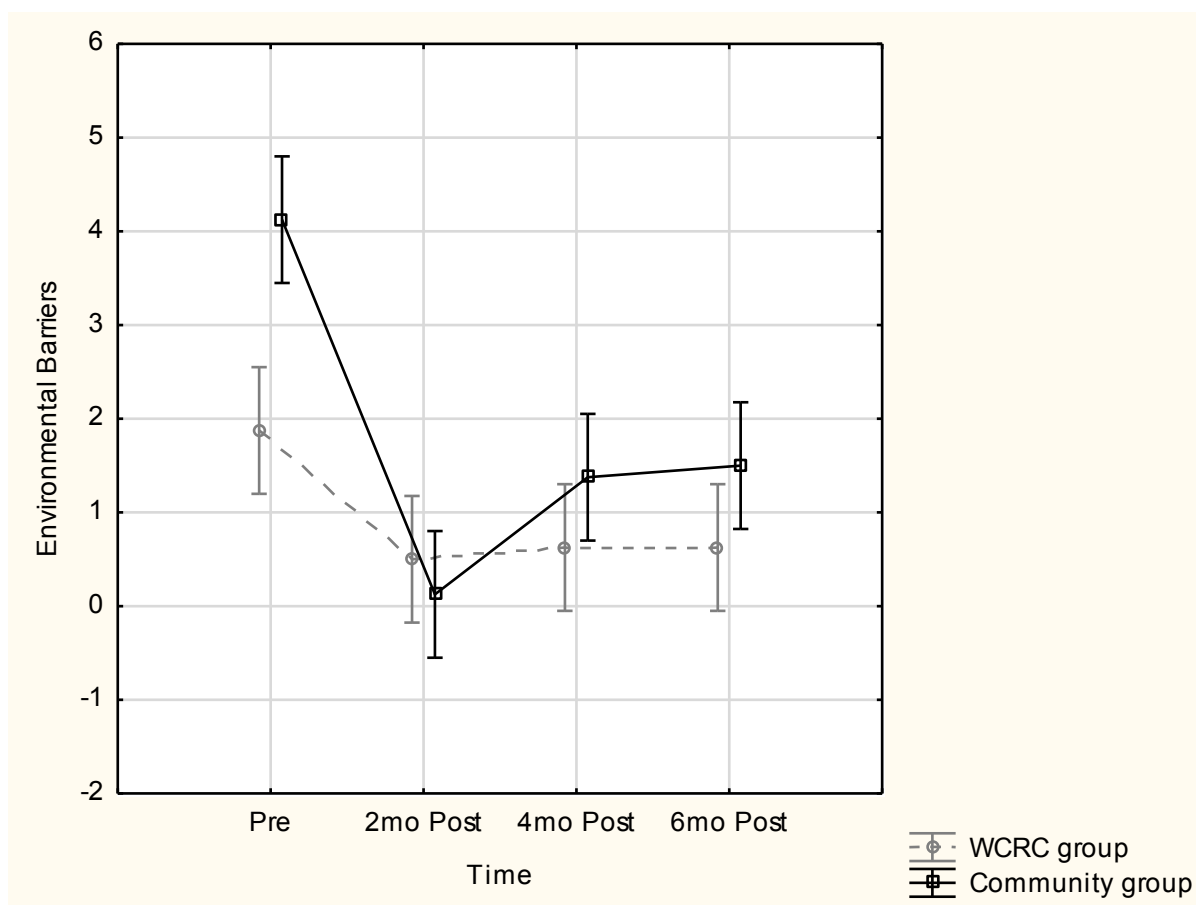
Environmental barriers were the most reported barriers in both groups. A significant difference was found between the Community group and the WCRC group over all four time points ( $p < 0.05$ ) and was particularly evident at baseline as indicated in figure 21. The Community group had nearly double the amount of barriers in comparison with the WCRC group at baseline. Significant differences were also observed in the number of barriers that were reduced within both groups over the course of the intervention ( $p < 0.05$ ). The main differences between the groups were found in the number of participants who indicated lack of facilities, lack of transport and the weather as barriers. More participants from the Community group reported these as barriers. Lack of transport, however, was the most reported barrier in both groups (62.5% WCRC group and 100% Community group). The weather was also a barrier mentioned by all the participants from the Community group and only by 25% of people from the WCRC group. The second most reported barrier in the WCRC group was also found by 87.5% of the participants from the Community group and included lack of facilities. Lack of adaptive equipment was a barrier, especially in the Community group (5/8 participants) and only mentioned by one of the participants in the

WCRC group. In terms of access and location of facilities the Community group seemed to be more adversely affected than the other group (62.5 % Community and 37.5% WCRC group).

Two months post-intervention the total barriers were reduced in both groups, from 15 to four and 33 to one in the WCRC and Community group, respectively ( $p < 0.05$ ). The only barrier that was present at two months post-intervention was the weather. This barrier, however, was reduced from 100 to 12.5% in the Community group, however, it increased within the WCRC group from 25% to 50%. The main barrier that remained consistent throughout the course of the post-intervention period was lack of transport. Although the initial number was reduced by 62.5% at two months post-intervention, it remained a problem in nearly half of the total participants by the end of the six months (3/8 WCRC; 4/8 Community). The barrier that changed most drastically was the weather and seemed to mainly impact the Community group. At six months post-intervention, all of the participants from the Community participants agreed that it was a major barrier to PA.

**Table 40: Change in environmental barriers over time for the different environments**

Barriers	WCRC Group				Community Group			
		% (n)			% (n)			
Environmental	Pre	2mo	4mo	6mo	Pre	2mo	4mo	6mo
Lack of facilities	50 (4)	0	0	0	87.5 (7)	0	0	0
Inaccessible facilities	12.5 (1)	0	0	0	37.5 (3)	0	0	0
Inconvenient location	25 (2)	0	0	0	25 (2)	0	0	0
Lack of adaptive equipment	12.5 (1)	0	0	0	62.5 (5)	0	0	0
Lack of transport	62.5 (5)	0	50 (4)	37.5 (3)	100 (8)	0	50 (4)	50 (4)
Weather	25 (2)	50 (4)	12.5 (1)	12.5 (1)	100 (8)	12.5 (1)	87.5 (7)	100 (8)
Other	0	0	0	0	0	0	0	0



$p < 0.01$  (group\*time effect)

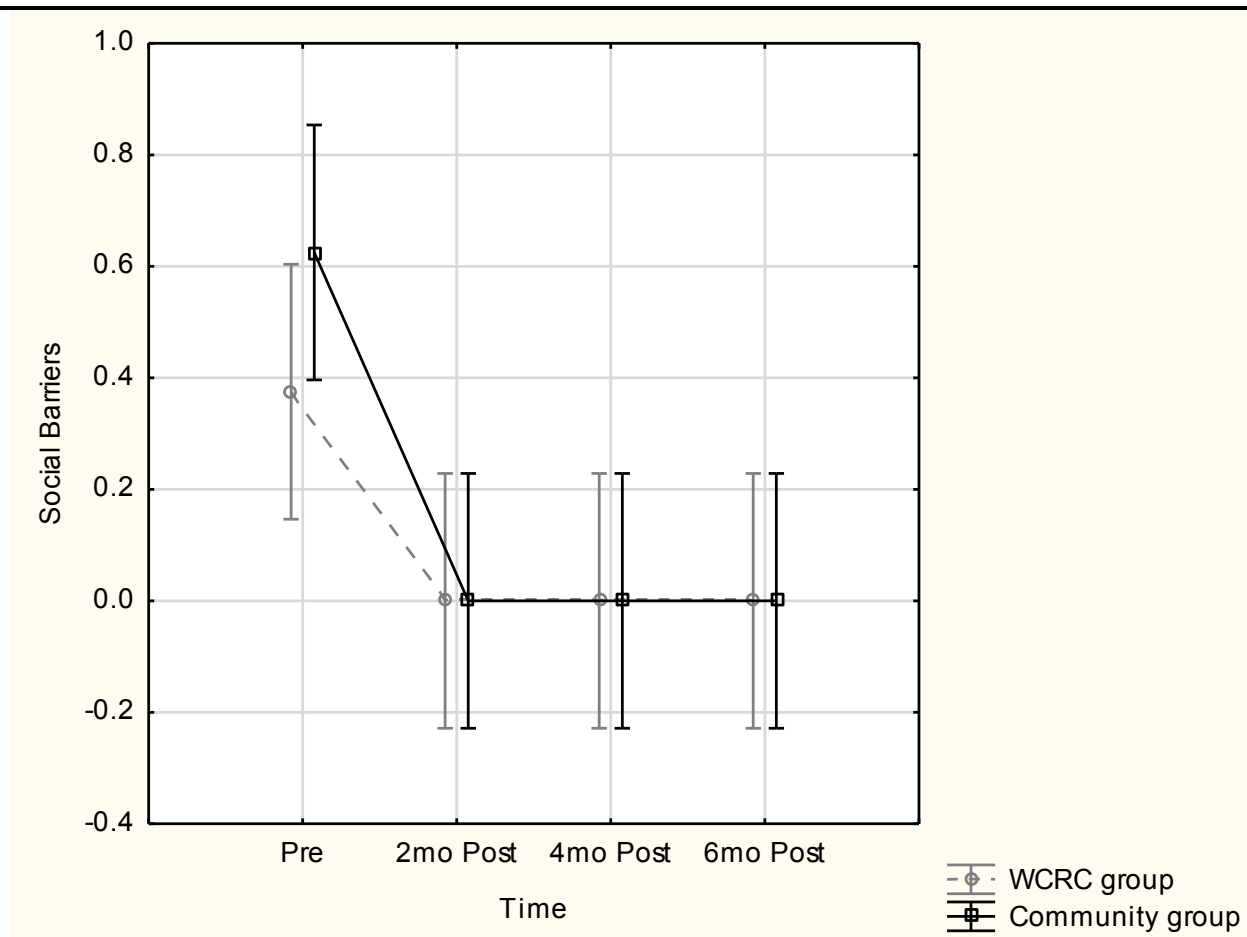
**Figure 21: The change in the total barriers over time between the two groups**

#### 5.5.4. Social Barriers

In comparison with the other barriers, the social barriers impacted the participants the least. No significant differences were found between the two groups ( $p > 0.05$ ) at all time points, however, significant differences were found over time within the groups ( $p < 0.05$ ). This was indicated by the complete elimination of the social barriers during the intervention as seen in table 41. The initial barriers were lack of family support and lack of role models mentioned by 12.5% participants in the WCRC group and Community group, respectively. Lack of information received from therapists seemed to have the greatest impact on the participants from both groups (25% WCRC group and 50% Community group).

**Table 41: Change in social barriers over time for the different environments**

Barriers	WCRC Group				Community Group			
	Pre	2mo	4mo	6mo	Pre	2mo	4mo	6mo
Lack of family support	12.5 (1)	0	0	0	0	0	0	0
Negative societal attitudes	0	0	0	0	0	0	0	0
Lack of role models	0	0	0	0	12.5 (1)	0	0	0
Lack of information received	25 (2)	0	0	0	50 (4)	0	0	0
Other	0	0	0	0	0	0	0	0



p > 0.05 (group\*time effect)

**Figure 22: The change in the total barriers over time between the two groups**

### 5.5.5. Program/Policy Barriers

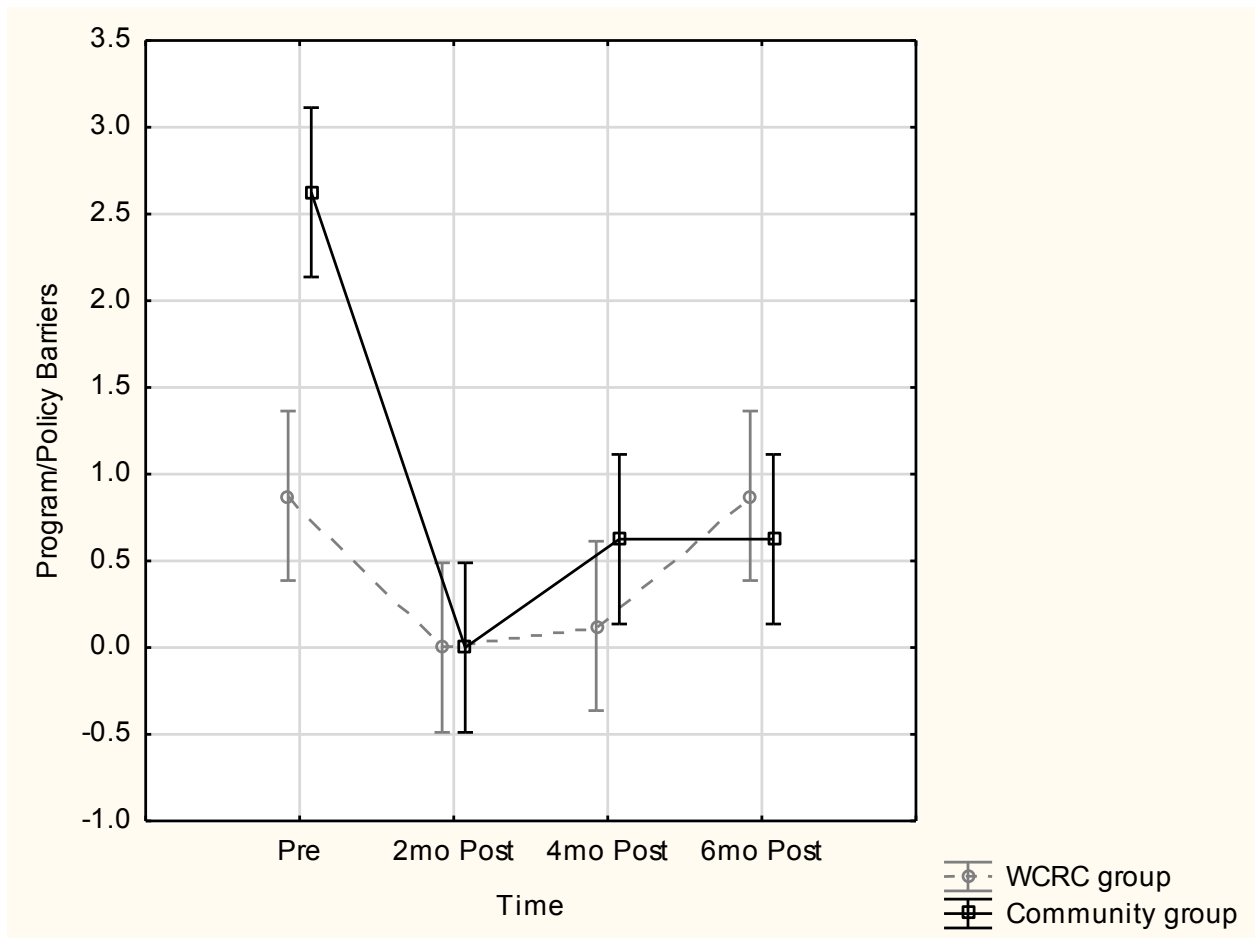
There was a significant difference found between the two groups in terms of the amount of program/policy barriers identified at baseline ( $p < 0.05$ ). The significant difference between the two groups at baseline was observed in the number of participants who selected lack of trained volunteers as a barrier. There was also a significant decrease found in the Community group over time ( $p < 0.05$ ). This is indicated by the results in table 40, which show that the Community group listed a greater number of program/policy barriers ( $n=21$ ) than the WCRC group ( $n=7$ ). In the case of the Community group the greatest program barrier was lack of trained volunteers (100%) and the fact that there were no programs (75%) within the community. In the WCRC group only 25% agreed that the above mentioned issues were barriers. Cost of programs and lack of staff capacity affected 37.5% of the participants in the WCRC group and 75% in the Community group.

According to the post-intervention research questionnaire, none of the barriers affected the individuals anymore, indicating a 100% reduction in both groups ( $p < 0.05$ ). However, during the course of the post-intervention period one particular barrier reappeared, namely lack of trained volunteers. At two months post, this barrier was eliminated, however, over time, it became an increasing concern to both groups. In the WCRC group the number increased to 25% and in the Community group to 62.5%. In the WCRC group an additional barrier was identified at six months post-intervention and prevented the participants from being PA. This barrier was staff that went on leave and no other staff members or volunteers were able to tend to sessions.

**Table 42: Change in program/policy barriers over time for the different environments**

Barriers	WCRC Group				Community Group			
		% (n)				% (n)		
Program/Policy	Pre	2mo	4mo	6mo	Pre	2mo	4mo	6mo
Lack of appropriate programs	25 (2)	0	0	0	75 (6)	0	0	0
Lack of inclusive programs	0	0	0	0	12.5 (1)	0	0	0
Cost of programs	25 (2)	0	0	0	37.5 (3)	0	0	0
Lack of staff capacity	12.5 (1)	0	0	0	37.5 (3)	0	0	0
Lack of trained volunteers	25 (2)	0	12.5 (1)	25 (2)	100 (8)	0	50 (4)	62.5 (5)
Lack of guidance by staff	0	0	0	0	0	0	0	0
Negative attitudes	0	0	0	0	0	0	0	0
Other	0	0	0	62.5 (5)	0	0	0	0



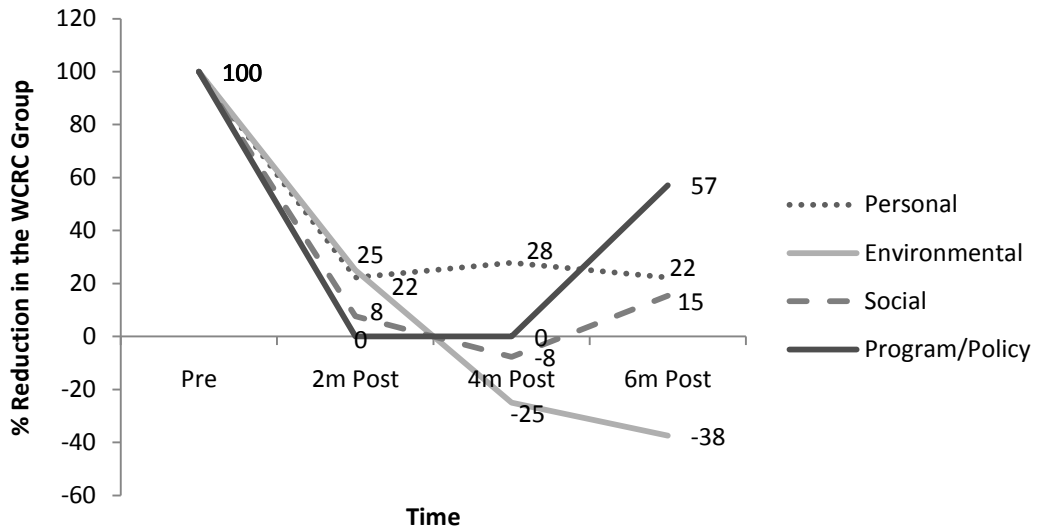


$p < 0.01$  (group\*time effect)

**Figure 23: The change in the total barriers over time between the two groups**

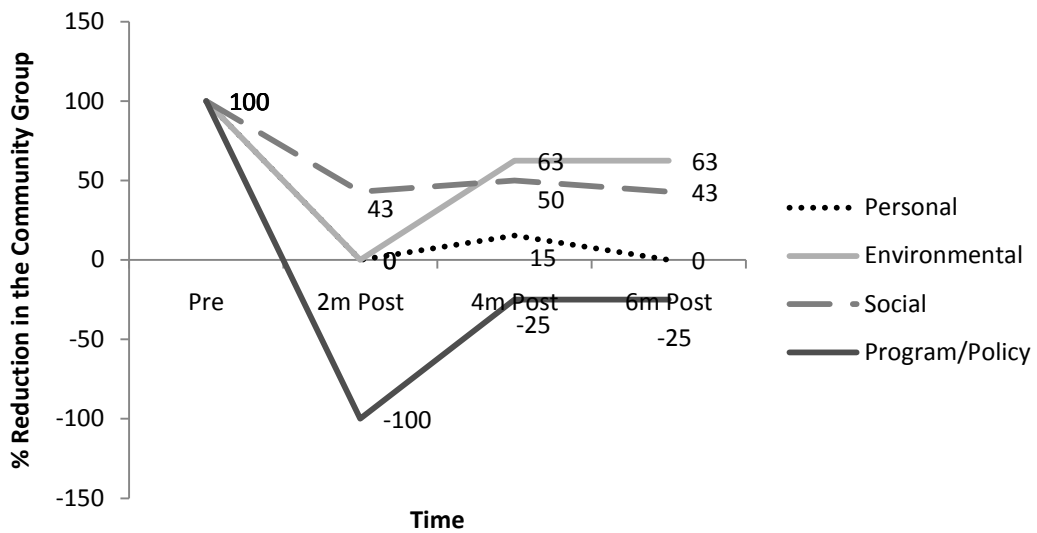
#### 5.5.6. Facilitators Reported by the Participants

In figures 24 and 25 the facilitators identified by the participants are summarized. Several common facilitators were identified by the two groups and the most commonly reported were the personal and social facilitators. Prior to the start of the intervention, 12 of the 16 participants indicated that PA makes them feel good (personal facilitator) and that it was a reason to be physically active. Friend and family support and positive encouragement from peers (social facilitators) were reported by ten participants as facilitators. The least reported facilitators were the program/policy facilitators. The rest of the results are further presented and discussed below.



\*p<0.05

**Figure 24: % Facilitator reduction in the WCRC group over time**



\*p<0.05

**Figure 25: % Facilitator reduction in the Community group over time**

### 5.5.7. Personal Facilitators

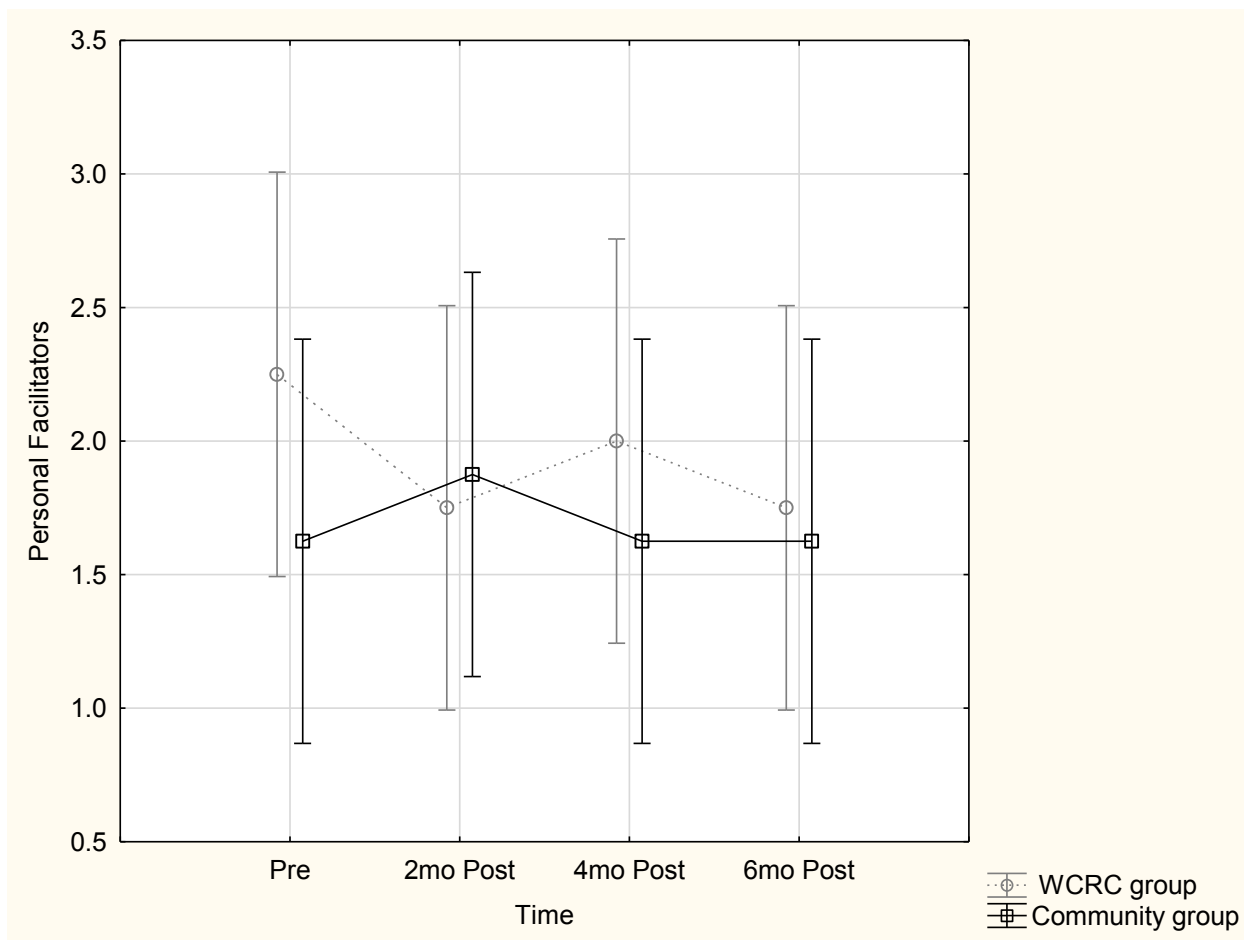
Under personal facilitators no significant differences were observed between the two groups over time ( $p>0.05$ ). According to the majority of the participants from the WCRC group, 75% said that a desire to be active, to improve self-esteem and feeling good were facilitators to exercise. In the Community group, the numbers were slightly lower and 50% said they had a desire to be active, 37.5% stated that they were active to improve their self-esteem and 75% said PA made them feel good.

In the WCRC group, the total number of facilitators was reduced from 18 to 14 after the eight-week intervention ( $p>0.05$ ). The desire to be active remained the same, but being PA to improve self-esteem and feeling good was reduced from 75% to 37.5% and from 75% to 62.5%, respectively. In the Community group, the facilitators total remained the same, but a desire to be active was increased and being PA to improve self-esteem decreased by 12.5% in each group.

Over the course of the post-intervention period the personal facilitators remained relatively the same for both groups. The only facilitator that changed in both groups was the desire to be physically active. This number was reduced from 75% to 50% in the WCRC group and from 62.5% to 37.5% in the Community group. By the end of the six month period, two additional facilitators were identified by both groups. These two additional facilitators were to lose weight and to keep fit.

**Table 43: Change in personal facilitators over time for the different environments**

Facilitators	WCRC Group				Community Group			
	Pre	% (n)			Pre	% (n)		
Personal	Pre	2mo	4mo	6mo	Pre	2mo	4mo	6mo
Desire to be active	75 (6)	75 (6)	62.5 (5)	50 (4)	50 (4)	62.5 (5)	37.5 (3)	37.5 (3)
Improve self-esteem	75 (6)	37.5 (3)	25 (2)	37.5 (3)	37.5 (3)	25 (2)	25 (2)	25 (2)
Feel Good	75 (6)	62.5 (5)	75 (6)	62.5 (5)	75 (6)	75 (6)	75 (6)	75 (6)
Other	0	0	0	25 (2)	0	0	0	25 (2)



$p > 0.05$

**Figure 26: The change over time in the total personal facilitators identified by the participants from both groups**

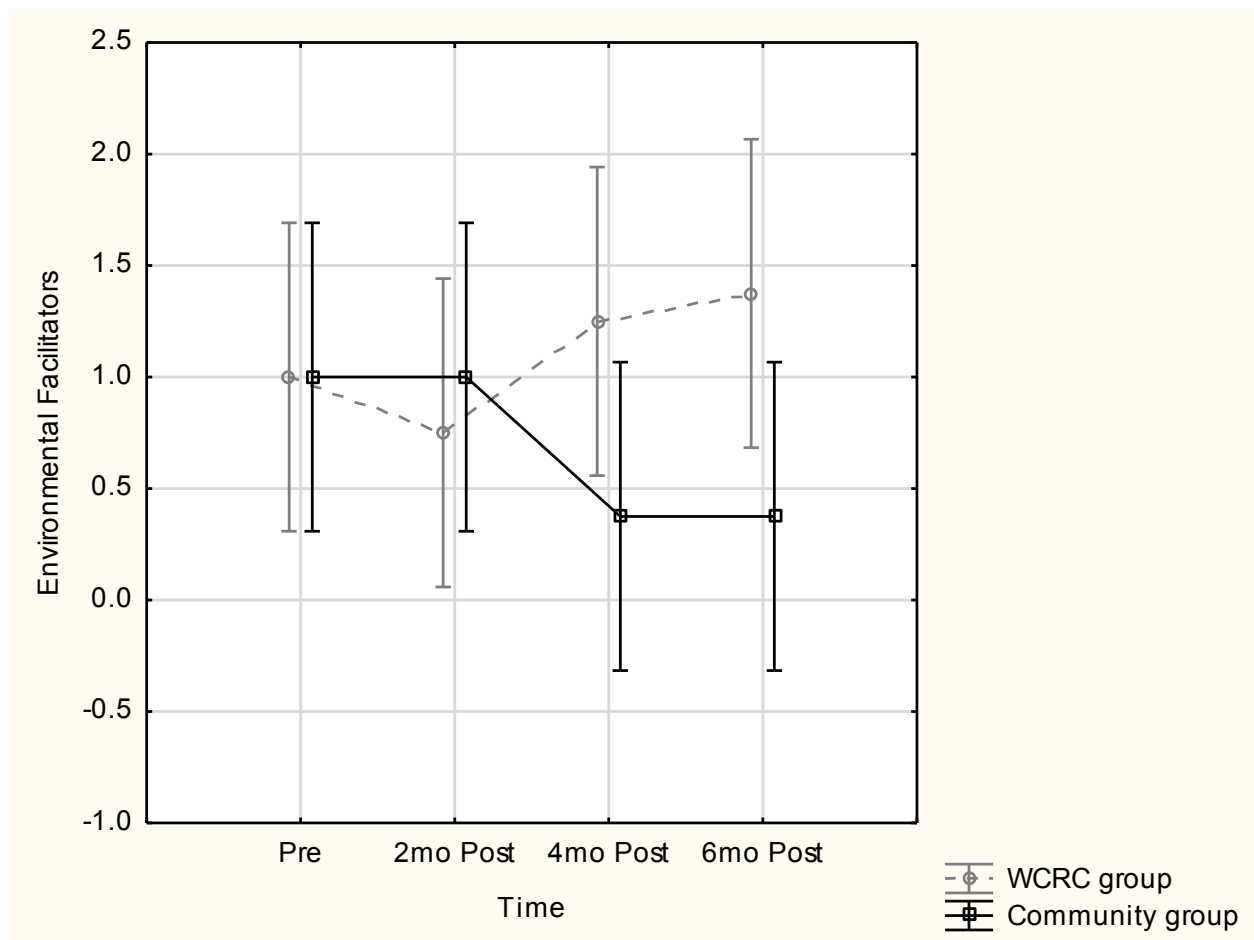
### 5.5.8. Environmental Facilitators

According to figure 27 there was no significant difference found between the two groups over the course of the intervention in terms of environmental barriers ( $p > 0.05$ ). However, at six months post-intervention, a significant difference was found between the two groups (WCRC group  $n = 11$  and Community group  $n = 3$ ) ( $p < 0.05$ ). Prior to the start of the intervention, accessible facilities and facilities that were in a safe location were mentioned by nearly half of the participants as facilitators to PA in both groups. Once again, the facilitators that were identified by the two groups were not significantly different ( $p > 0.05$ ). The major changes in facilitators were observed in the Community group. Accessible facilities and the fact that facilities were in a safe location were reduced by 25% in each group. In the WCRC group, these facilitators remained relatively constant throughout the rest of the intervention.

Overall, the environmental facilitators increased in the WCRC group from eight to 11 ( $p>0.05$ ), but decreased from eight to three in the Community group ( $p>0.05$ ). No additional facilitators were identified by the participants.

**Table 44: Change in environmental facilitators over time for the different environments**

Facilitators	WCRC Group				Community Group			
	% (n)				% (n)			
Environmental	Pre	2mo	4mo	6mo	Pre	2mo	4mo	6mo
Accessible facilities	50 (4)	50 (4)	50 (4)	62.5 (5)	50 (4)	62.5 (5)	25 (2)	25 (2)
New facilities in rural areas	12.5 (1)	0	0	12.5 (1)	0	0	0	0
Transport	0	0	25 (2)	25 (2)	12.5 (1)	25 (2)	0	0
Safe location	37.5 (3)	25 (2)	50 (4)	37.5 (3)	37.5 (3)	12.5 (1)	12.5 (1)	12.5 (1)
Other	0	0	0	0	0	0	0	0



$p > 0.05$

**Figure 27: The change over time in the total environmental facilitators identified by the participants from both groups**

### 5.5.9. Social Facilitators

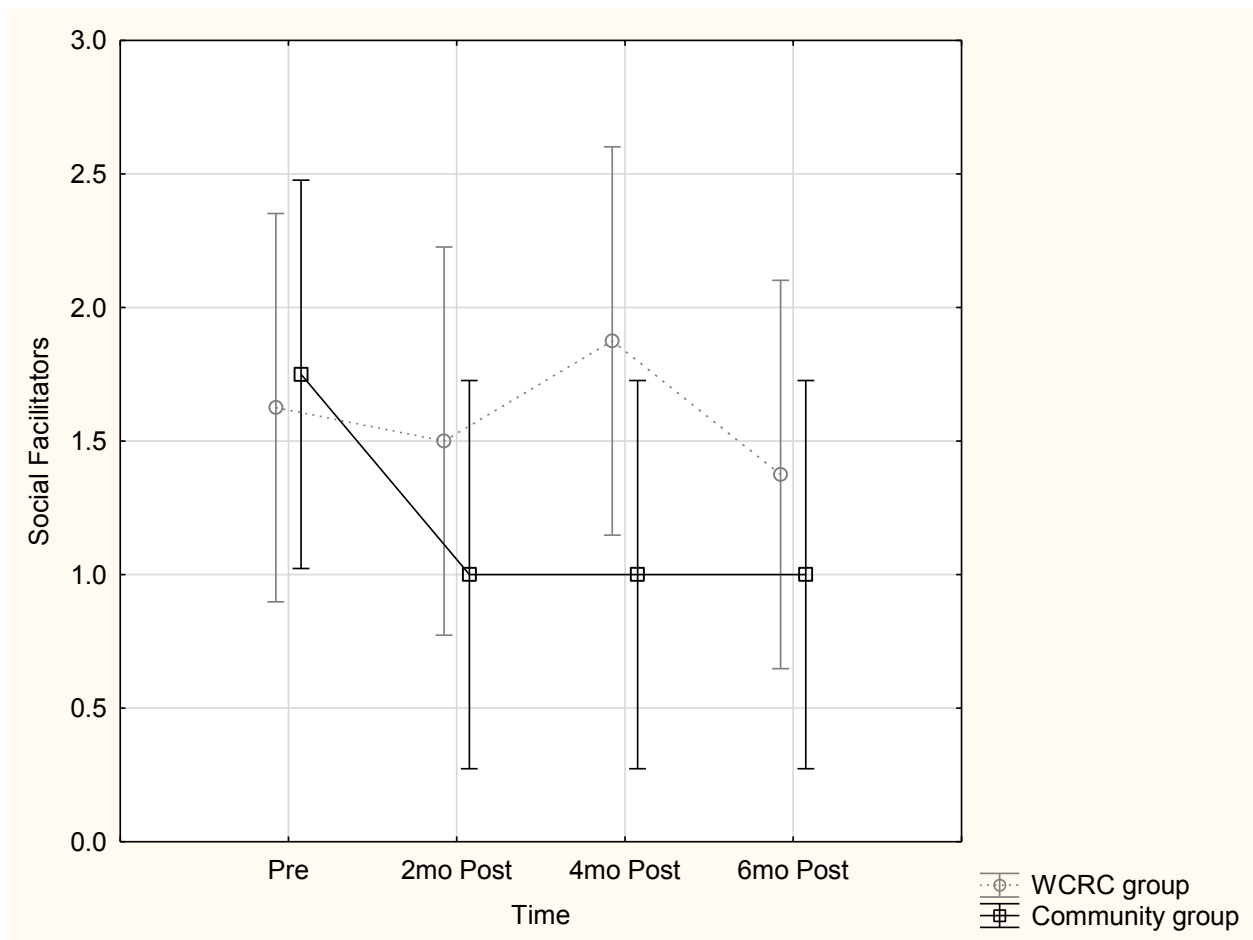
There were no significant differences found between the two groups over all the different time points ( $p > 0.05$ ). Friend and family support and positive encouragement from peers were the greatest facilitators to the participants prior to the intervention in both groups. Friend and family support was more significant to the WCRC group and was reported by 75% of the participants' pre-intervention and by 87.5% post-intervention. For the Community group, positive encouragement from peers seemed to motivate the participants more to start PA, as this number was reduced from 75% to 37.5% post-intervention. Having a role model was also a facilitator mentioned by 37.5% of the participants in the Community group and by only 12.5% in the WCRC group. However, post-intervention, this was no longer a facilitator to the participants in the Community group.

During the six months' intervention the social facilitators decreased in both groups. In the WCRC group social facilitators decreased from 13 to 11 and in the Community group from

14 to eight ( $p>0.05$ ). Friend and family support was the only facilitator that increased and remained relatively constant in both groups during the post-intervention period. Positive encouragement from peers was initially important to more than half of the participants, but with time, became less important and decreased in both groups. In the WCRC group, it was reduced by 37.5% and in the Community group, by 62.5%.

**Table 45: Change in social facilitators over time for the different environments**

Facilitators	WCRC Group				Community Group			
		% (n)				% (n)		
Social	Pre	2mo	4mo	6mo	Pre	2mo	4mo	6mo
Friend and family Support	75 (6)	87.5 (7)	100 (8)	100 (8)	50 (4)	50 (4)	75 (6)	75 (6)
Positive encouragement from peers	50 (4)	50 (4)	25 (2)	12.5 (1)	75 (6)	37.5 (3)	12.5 (1)	12.5 (1)
Positive societal attitudes	12.5 (1)	12.5 (1)	25 (2)	12.5 (1)	12.5 (1)	0	0	0
Role models	12.5 (1)	0	12.5 (1)	12.5 (1)	37.5 (3)	0	0	0
Adequate information from Therapists	12.5 (1)	0	12.5 (1)	0	0	12.5 (1)	0	0
Other	0	0	0	0	0	0	0	12.5 (1)



$p > 0.05$

**Figure 28: The change over time in the total social facilitators identified by the participants from both groups**

#### 5.5.10. Program/Policy Facilitators

Throughout the intervention there were no significant differences between the groups regarding the total program/policy facilitators change over time ( $p > 0.05$ ). The main difference between the Community and the WCRC group regarding program/policy barriers was observed prior to the intervention. Initially, good quality programs motivated 37.5% of the WCRC participants, while trained volunteers motivated 25% of the Community group to be physically active.

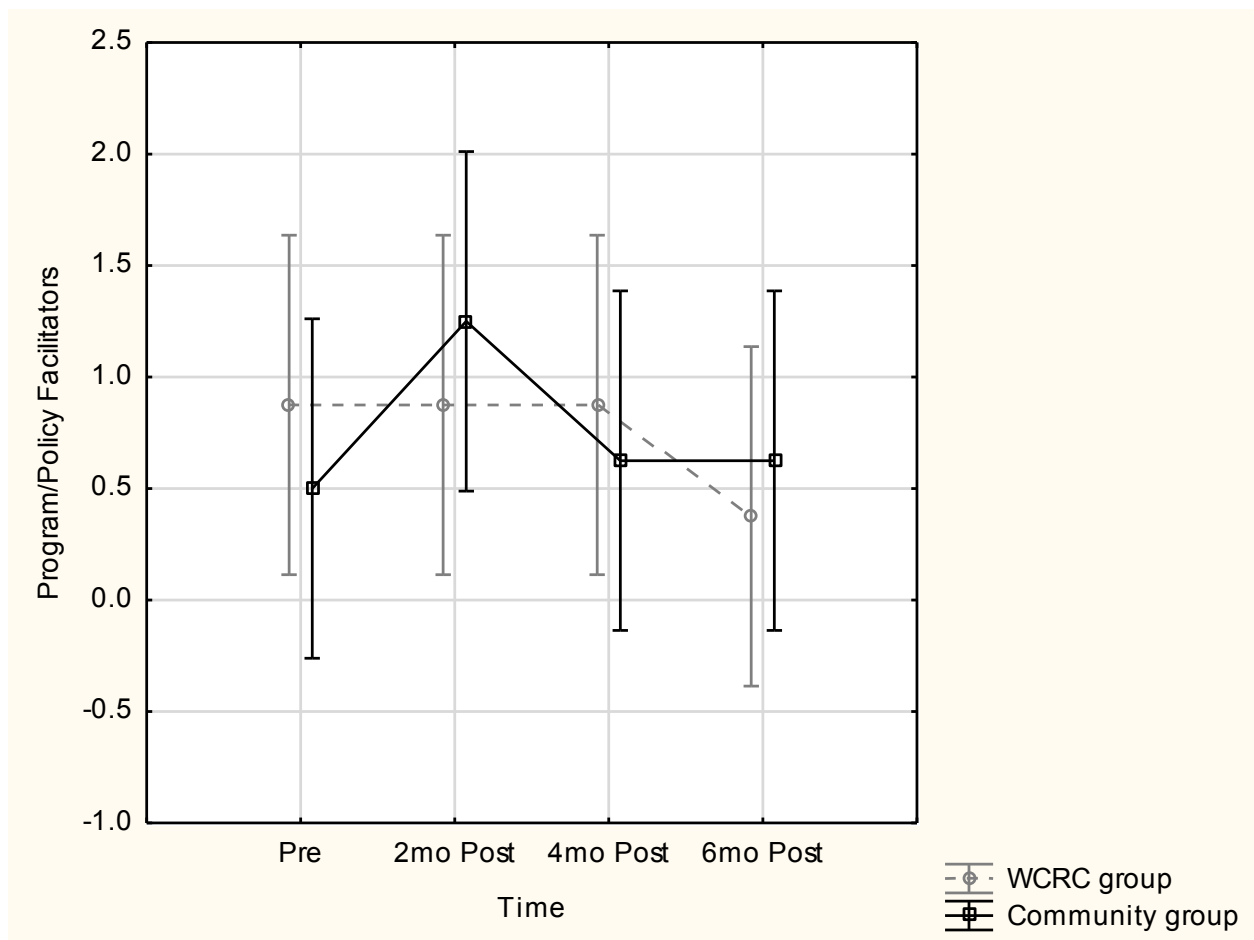
During the pre-and post-intervention period the total facilitators for the WCRC group remained the same until the last data collection point when it was reduced from 87.5% to 37.5% ( $p > 0.05$ ). In the Community group the total number of facilitators was increased from 50% to 62.5% by the six month post-intervention period ( $p > 0.05$ ).



During the post-intervention period the most important facilitators were identified as having enough trained volunteers (Community group) and having enough staff (WCRC group). The facilitator of having good quality programs, initially, was no longer the most important reason for staying physically active by six months post-intervention.

**Table 46: Change in program/policy facilitators over time for the different environments**

Facilitators	WCRC Group				Community Group			
		% (n)				% (n)		
Program/Policy	Pre	2mo	4mo	6mo	Pre	2mo	4mo	6mo
Quality programs	37.5 (3)	50 (4)	37.5 (3)	0	12.5 (1)	12.5 (1)	12.5 (1)	12.5 (1)
Skilled staff	25 (2)	25 (2)	37.5 (3)	0	0	25 (2)	12.5 (1)	12.5 (1)
Trained volunteers	12.5 (1)	12.5 (1)	12.5 (1)	0	25 (2)	37.5 (3)	37.5 (3)	37.5 (3)
Enough staff	12.5 (1)	0	0	37.5 (3)	12.5 (1)	25 (2)	0	0
Other	0	0	0	0	0	0	0	0



$p > 0.05$

**Figure 29: The change over time in the total program/policy facilitators identified by the participants from both groups**

### 5.5.11. Conclusion of the Results

The main difference that was observed between the Community and the WCRG group was the reduction in the total barriers that occurred during the entire period of six months. In the Community group the total barriers were reduced by 76% and in the WCRG group by 64%. The environmental barriers were the most significantly reduced in the Community group (64% reduction). The greatest reduction in barriers in the WCRG group was evident in the personal barriers, namely a reduction of 81%. Although the number of facilitators was expected to increase with a reduction in the number of barriers, this was not the case. The reduction in facilitators over the study period was, however, much less than the reduction in the barriers.

## 5.6. Discussion: Change in Barriers over Time

To the researcher's knowledge there are currently no studies that have examined the change in barriers and facilitators after an intervention and over time in PWaSCI. The

majority of the studies only report on the barriers and facilitators that people without disabilities, PWD and PWaSCI face in being physically active (Tasiemski *et al.*, 2004b; Rimmer *et al.*, 2004; Vissers *et al.*, 2008; van den Berg-Emons *et al.*, 2008; Crawford and Stodolska, 2008; Kehn and Kroll, 2009; Stephens, Neil and Smith, 2012; Malone *et al.*, 2012). People are physically inactive for many reasons, which include lack of self-efficacy and enjoyment, lack of safe neighbourhoods, insufficient support from others and negative beliefs about the benefits of exercise (Kerstin, Gabriele and Richard, 2006). For PWD the situation is exacerbated and additional barriers such as outdoor climate, lack of transportation, inadequate accessibility, long commuting distances and lack of accessible buildings contribute to physical inactivity (Kerstin *et al.*, 2006). PA is a crucial component to overall wellbeing and the barriers that prevent PWD from being physically active, can affect their mental and physical states (Putnam *et al.*, 2003) which, ultimately affects health and wellness.

Before the start of the intervention, the main barriers identified by all the participants were the environmental and personal barriers. This is consistent with previous research done by Jaarsma *et al.* (2014) and Louw, Van Biljon and Mugandani (2012). Although the program/policy barriers did not seem to have a significant impact on the WCRC group, it did prevent the Community group from being physically active. The social barriers seemed to have a minimal impact on the participants from both groups. Initially, the Community group faced more barriers. However, by the end of the intervention, this total was reduced by 76%. The greatest difference between the two groups was evident in the environmental and program/policy barriers. In the WCRC group environmental barriers totalled 15, whereas, in the Community group, this number was more than double (33). In the program/policy barriers there was a threefold difference between the groups. In the personal and social barrier categories the numbers as well as the type of barriers that were identified, were very similar. This could possibly suggest that for a community based group the greatest barriers are the immediate environment and the program/policy barriers.

The purpose of identifying the barriers prior to the start of the intervention was twofold. Firstly, the aim was to see whether the barriers faced within South Africa were similar to those from developed and other developing countries. Secondly, the purpose was to reduce or eliminate the barriers, where possible, in order to foster health and wellness in PWaSCI through PA. The first part was discussed in Chapter four and the results showed that although PWaSCI in South Africa face similar barriers to other countries, with the most prevalent being lack of transport and lack of access and availability of facilities, PWaSCI in a

developing country, face unique challenges, such as not having enough opportunities to be physically active and the weather which is indirectly impacted by the lack of transport available.

### 5.6.1. Personal Barriers

During the intervention, the barriers that were targeted were lack of finances to pay for a PA program, lack of time and lack of knowledge/skill. Lack of finances as a barrier was eliminated as the program did not incur any cost upon the participants in terms of paying for access or for the PA program. By providing a facility that is within a short and safe travelling distance from the participants' place of residence further contributed to reducing this barrier within the Community group (this is further discussed under environmental barriers). Lack of time was targeted as participants only had to commit to attend two sessions per week for approximately 90 minutes per session. Lack of knowledge/skill was reduced since the participants were guided, trained and assisted during the PA sessions by trained staff and volunteers.

The intervention was shown to be successful in reducing and eliminating some of the barriers mentioned above. In the WCRC group, the barriers were reduced from 16 to three and in the Community group from 15 to one. In phase I of the study, injury level was a barrier to most PWaSCI. Interestingly, in phase II the participants who indicated that their injury level was a barrier was reduced from 75% (n=12) to zero by the end of the six months. A possible explanation could be that the participants did perceive their injury level as a barrier, but, during the course of the intervention, that perception was changed by the reduction in the barriers they faced and by their improved physical abilities.

During the post-intervention period, secondary conditions (bladder infections, pressure sores and pain) were the only personal barrier identified by the participants. Secondary conditions are common in PWaSCI and affected both the WCRC and the Community group at different time points. During the six month intervention period, both groups had between five to six instances where one or more participants had secondary conditions present. In the Community group these conditions were eliminated by the six month post-intervention data collection point. However, three participants in the WCRC presented with pressure sores at six months post-intervention.

According to Rimmer and Henley (2013) secondary conditions are very common amongst PWaSCI and can be a major limiting factor in the promotion of good health, independence and social integration in PWD (Rimmer and Rowland, 2008). Pressure ulcers and urinary

tract infections (or bladder infections) are some of the major causes for rehospitalisations (Walter, Sacks and Othman, 2002; Cardenas *et al.*, 2004) and amongst the most common conditions in PWaSCI (Adriaansen *et al.*, 2013), especially in people with a complete injury (DeJong, 2013). In a study conducted by Bloemen-Vrencken (2005) bladder and bowel problems were also the most frequently occurring problems and in the study done by Charlifue, Lammertse and Adkins (2004) pressure ulcers were the most frequent complications. Pressure sores are relatively common amongst PWaSCI and the incidence can range from 23%-33% or more per year (Clark *et al.*, 2006).

Despite the benefits of PA and the advances that have been made in the medical management of conditions (Levins *et al.*, 2006; Kehn and Kroll, 2009), they are unavoidable in some instances and PWaSCI remain vulnerable to tissue breakdown (Garber, Rintala, Hart and Fuhrer, 2000). Pressure sores can be caused by moisture, poor nutrition, acute lesions and smoking (Krause and Broderick, 2004). Although unavoidable in certain situations, they need to be reduced and managed as the condition ultimately also interferes with community reintegration (Garber *et al.*, 2000). Bladder infections mainly develop as a result of a neurogenic bladder and the need for catheterization (Brusch, 2014). According to Edokpolo, Stavris and Foster (2012) bladder infections occur in 20% of PWaSCI. During the intervention, the amount of bladder infections was also reduced and one possible reason could be that the participants were encouraged to increase their fluid intake especially whilst being physically active and during high temperatures. According to NHC (2013), drinking water regularly throughout the day may help to avert urinary tract problems such as infections.

Another reason could be that with time and increasing age, the risk of bladder infections is reduced, but the chances for developing pressure sores are increased, especially in paraplegics using manual wheelchairs (Hitzig *et al.*, 2010). According to Tawashy *et al.* (2009) and Kehn and Kroll (2009) the reduction in secondary conditions is related to the amount and type of PA the person does. In the study done by Kehn and Kroll (2009) they found that paraplegics who played sport were more successful in avoiding secondary conditions than their sedentary counterparts. In the study conducted by Tawashy *et al.* (2009) in community dwelling PWaSCI, the researchers found that greater participation in mild intensity PA was associated with reduced secondary conditions.

Pain was another secondary condition that was mentioned at the two months' post-intervention point and although PA is associated with reduced pain levels in PWaSCI (Tawashy *et al.*, 2009; Stephens *et al.*, 2012), certain pain in PWaSCI may be chronic and

persist throughout life (Whalley-Hammell, 2010). Tawashy *et al.* (2009) found that higher levels of mild and high intensity PA were correlated with lower levels of pain in community dwelling PWaSCI. Similarly, Stephens *et al.* (2012) found that in athletes with a SCI who partook in sport reported less pain and spasms and noted pain relief as one of the benefits of partaking in sport. In the current study, the type and level of pain were not specified in the research questionnaire in order to distinguish between acute and chronic pain. This is an important aspect as chronic pain affects mood, function, QOL and ADL (Chiodo *et al.*, 2007; Whalley-Hammell, 2010). Although it cannot be inferred in the current study that the PA program led to reduced secondary conditions the CDC (2015) asserted that regular PA is one of the most important things a person can do for his/her health.

One final barrier not previously identified, was employment. At the start of the study, none of the participants were employed, but by the end of the six months, one participant gained employment and could therefore not attend the sessions as they took place during work hours. Employment was also a barrier identified by Rauch, Fekete, Cieza, Geyh and Meyer (2013). Vanderbom (2013) reported that for some employed participants with Spina Bifida it was difficult to find time for PA. Very few articles report on work as a barrier to PA, since most people are able to participate in PA after work.

### 5.6.2. Environmental Barriers

Environmental barriers made up the majority of the identified barriers in this study. It was therefore important that these barriers be reduced as much as possible since environments that lack relevant resources or pose barriers (such as weather and high crime rate) may be the reason for peoples' physical inactivity (Sallis, Johnson, Calfas, Caparosa and Nichols, 1997). The environmental barriers that were targeted in this study were to reduce the dependence on transport for the Community based group by identifying training environments that were close and accessible to the group members. According to Sillis *et al.* (1997) PA can take place in a variety of settings such as homes, fitness centres, parks and the work place. This was illustrated in the current study, where one setting was a formal exercise facility at a rehabilitation centre and the others a community centre and a church building. Another aspect that affects PA participation is the contribution individuals can make, by for example purchasing equipment (Sillis *et al.*, 1997). Lack of adaptive equipment was therefore eliminated by providing both groups with the appropriate adapted equipment.

The intervention was shown to be successful in eliminating the barriers related to access, facilities and equipment. The major distinction between the two groups was evident in the initial barriers that were identified, namely, lack of facilities, lack of equipment, lack of

transport and the weather. The Community group listed more than double the environmental barriers than the WCRC group. However, most of the barriers identified by the Community group were also reduced. This was anticipated, especially within the South African context where there are very few facilities that are accessible, and few or no programs that are run within communities that cater for PWD. According to Brownson, Baker, Housemann, Brennan and Bacak (2001), access to locations and facilities where people can actively engage in PA, correlate positively with physical activity behaviour in adults. In their review, a correlation was also found between the quantity of exercise equipment available and physical activity, as well as people having access to both free and paid facilities (Brownson *et al.*, 2001). From pre-to post-intervention the total barriers were considerably reduced in both groups (from 15 to four and 33 to one in the WCRC and Community group, respectively). However, two environmental barriers remained dominant in the intervention, namely lack of transport and the weather.

Lack of transport is a major barrier listed by most people (Scelza *et al.*, 2005; Crawford and Stodolska, 2008; Malone *et al.*, 2012). In the Community group none of the participants had their own means of transport. Initially, this was not a problem, because the participants were able to use their wheelchairs to get to the facility. However, as the weather started to change and winter approached, this became an increasing concern. In the Community group, lack of transport was initially decreased from 100% to 12.5% (pre-and post-intervention) but, over time, affected half of the participants. In the WCRC group, the same trend followed and at six months 37.5% reported lack of transport as a problem. This can possibly be explained by the weather having changed and that during the winter months when it was cold and rainy, it was not possible to commute by wheelchair alone.

The weather became an increasing concern over time, especially in the Community group. Initially, all the participants from the Community group and only 25% of the participants from the WCRC group mentioned it as a barrier. At the end of the intervention, 12.5% of the participants from the WCRC and everyone in the Community group reported it as a barrier. The weather seemed to mainly affect participants who manually propel their wheelchairs, or rely on their wheelchairs as a means of transport. Another possible explanation for the difference between the two groups could be explained by the weather on the day the questionnaire was completed. Since testing and completion of the questionnaires took place on different days during the same week for each group, it is possible that the weather conditions were different and therefore influenced the participant's perception on that day. The intervention started in autumn when the temperatures were neither hot nor cold and the program ended in winter. The problem of bad weather prohibiting people from being

physically active is further illustrated in the review by Tucker and Gilliland (2007) who found that poor or extreme weather to be a barrier to PA in various populations from eight different countries. In another review done by Chan and Ryan (2009), the authors stated that ambient weather conditions may affect PA and therefore human health. The authors made specific inferences to precipitation in that it has the largest correlation to PA, and negatively impacts PA, which was also seen in this study.

### 5.6.3. **Social Barriers**

The social barrier that was challenged in the study was the lack of information that the participants received regarding PA, before being discharged from the hospital. Prior to the intervention, 25% of the participants from the WCRC group and 50% from the Community group mentioned that they did not receive sufficient information regarding PA. The discrepancy between the two groups could be explained by the fact that the participants in the WCRC group were hospitalised at the WCRC where they may have had exposure to the formal exercise setting prior to being discharged and that they were, therefore, informed about PA. A possible reason for lack of information in the Community group could be that therapists did not inform the participants of facilities that catered for PWaSCI living in different communities, as such facilities were not available. Some of the older participants may not have been informed about PA and opportunities as there was neither information, nor facilities available that catered for PWaSCI at that time. By providing the participants with a facility where they could be physically active and with the necessary information and education, this barrier was completely eliminated.

The second barrier that was targeted and eliminated in the intervention was the lack of social support (from friends or family) and the lack of role models. By providing the participants with an environment where they could be physically active together, immediate support was provided and friendships established. The participants encouraged one another and based on the researcher's observations, some even became role models. This is further supported by the increasing number of participants indicating friend and family support as facilitators by the end of the intervention.

### 5.6.4. **Program/Policy Barriers**

Prior to the start of the intervention program/policy barriers seemed to pose a greater obstacle to PA in the Community group. This was indicated by the number of barriers that were identified by the groups (Community group 21: WCRC group 7). The majority of the barriers were related to PA programs and staff. Hence, a PA program was created that carried no cost to the participants, provided the participant with a PA program that was



accessible and suitable and by providing enough trained volunteers to assist and run the program. The success of the intervention in removing these barriers was illustrated in the Community group where the total number of barriers was reduced from 21 to zero, from pre to post-intervention.

For the Community group, the greatest program barrier prior to the intervention was lack of trained volunteers and the fact that there were no programs within the community (100% and 75% of the participants, respectively). In the WCRC group only 25% of the participants reported the above mentioned as barriers. The reason for this was that the environment that catered for the WCRC group was a previously established facility, already fitted with equipment and manned by a staff member. Cost of programs and lack of staff capacity also affected both groups. The WCRC group was, once again, affected to a lesser extent. All of the above-mentioned barriers were either reduced or completely eliminated in both groups, except for one. Lack of trained volunteers was the only barrier previously identified that had increased and affected 62.5% of the participants in the Community group and 25% in the WCRC group. Although the participants continued to attend sessions, they did not necessarily receive the assistance that was required. The Community group was divided into two geographical areas. In the one group the number of volunteers remained the same, which was indicated by enough trained volunteers being a facilitator to the remaining 37.5% of the participants. However, in the other group, the number of volunteers decreased by two individuals and therefore, became a barrier to the remainder of the participants (62.5%).

The majority of research that reports on program/policy barriers, include lack of experience amongst fitness centre staff (Scelza *et al.*, 2005), lack of funds to hire specialists and qualified staff (Crawford and Stodolska, 2008) and the qualification or skills of supervision as being inadequate (Shakespeare and Kleine, 2013; Jaarsma *et al.*, 2014). The similarity between this study and the existing literature is the lack of trained volunteers or staff. The difference in the current study is the reliance on volunteers versus employed staff. This also highlights the difference between a developing country and a developed country in terms of offering employment opportunities to facilitate PA among marginalised groups or within poor communities. This is supported by Johnson (2009) who also identified a lack of community based instructors as barriers to PA.

In the WCRC group, a new barrier was identified by the end of the six-month-post-intervention period. The barrier can be classified under “not having enough staff”. The participants could not attend the PA sessions, because the staff member went on leave and therefore, the sessions had to be cancelled due to lack of staff members.

### 5.6.5. Conclusion

Although individual factors such as personal barriers play a major role in PA behaviour, the social and environmental aspects are crucial and according to McNeill *et al.* (2006), are the modifiable determinants of PA. This was illustrated in the study, in that the majority of these barriers were removed through the intervention. Although the majority of the barriers were reduced, time did show that some barriers might be linked to seasonal changes and others to personal choices. The most prominent barriers that remained included lack of transport (both groups), the weather (mainly Community group), and lack of trained volunteers (one specific group from the Community group). Although these barriers remained, only one participant stopped attending sessions due to employment. The above-mentioned barriers may have prevented the participants from being able to attend all the sessions, but did not lead to PA termination.

It is evident from the above that a community based PA program that is run by trained volunteers is possible and should become a government incentive to assist PWaSCI towards leading a more active and healthy lifestyle. By identifying the accessible community based facilities, providing basic equipment and trained volunteers, PWaSCI are able to achieve health and wellness as was illustrated by the improvement in their physical abilities and mRNLI scores. Not only will this reduce the pressure on the economy by reducing the number of hospitalisations due to secondary conditions, but it will help improve PWaSCI QOL and reintegration. This further supports Stephens *et al.* (2012) who stated that health promotion and increased PA can improve QOL and life satisfaction in PWaSCI.

## 5.7. Discussion: Change in Facilitators over Time

Physical activity within the SCI population is important for maintaining health and independence (Kerstin *et al.*, 2006). It is therefore central to understanding what facilitates the incorporation of PA into everyday life. Personal and social facilitators were the most often reported facilitators. This is not surprising, as it involves the human aspect of interaction and motivation. The reported facilitators were very similar in both groups. This possibly suggests a certain degree of homogeneity with regards to what motivates people to stay physically active. Although the total facilitators were reduced over the six-month period in both groups, the participants remained motivated to stay physically active.

### 5.7.1. Personal Facilitators

Although there are many PWaSCI who are not physically active, there are, indeed PWaSCI who adopt an active lifestyle (Kerstin *et al.*, 2006; Tawashy *et al.*, 2009). According to

Kerstin *et al.* (2006) the personal factors that contribute to an active lifestyle include enjoyment, fitness, competition and maintaining mental and physical health. In the current study, the personal facilitators were slightly different. In the WCRC group, the majority identified a desire to be active, improve self-esteem and feeling good as facilitators to PA. In the Community group, the numbers were slightly lower, but the same facilitators were identified. During the course of the intervention the number of personal facilitators was slightly reduced in the WCRC group, however, it remained relatively the same for the Community group. The main difference that was noted was a change in focus or priority and was indicated by additional facilitators that were identified by the participants. The additional facilitators that contributed to continued PA participation were that PA helps to keep fit, improve strength, relieve stiffness, improve mobility and lose weight. These facilitators were also identified in Louw *et al.* (2012) in the able-bodied population and by Wu and Williams (2001) in PWaSCI. The facilitators in this study shifted from a personal aspect to the benefits of PA that the participants experienced. This result possibly suggests that the facilitators that help PA initiation may need to change over time and focus on what the participants are getting out of the PA program, i.e. the benefits that are to be gained.

### 5.7.2. Environmental Facilitators

Since the environment posed one of the greatest barriers to PA, it was important to turn them into facilitators, especially within the Community group. The safe location and accessibility of the facilities were the greatest motivators to PA in both groups at pre-and six-month post-intervention. This is supported by Brownson *et al.* (2001) who stated that neighbourhood safety may be directly related to PA rates. Accessible facilities remain an important facilitator and according to Malone *et al.* (2012) policy changes should be in place to encourage accessibility of buildings. This is supported by Rauch *et al.* (2013) who stated that the accessibility of places has the potential to influence the engagement in PA.

Although the total number of facilitators was reduced in the Community group, during the intervention it was increased from eight to 11 in the WCRC group. A possible reason for this might be that other facilitators took precedence over the barriers that had been eliminated already, since there was neither change in venue nor a compromise in the safety of the participants in the Community group.

### 5.7.3. Social Facilitators

Friend and family support and positive encouragement from peers were the greatest social facilitators initially identified by the participants in both groups. According to Kerstin *et al.* (2006), these factors are sometimes needed for PWaSCI to be physically active. This is

consistent with the literature in that most research states social support, development of social contacts, role models and other PWD as good introductory agents for PWaSCI to get involved (Pluym, Keur, Gerritsen and Post, 1997; Page, O'Connor and Peterson, 2001; Stephens *et al.*, 2012; Jaarsma *et al.*, 2014).

For the WCRC group, friend and family support had the greatest impact throughout the intervention and post-intervention periods. For the Community group, positive encouragement from peers with disabilities and role models seemed to motivate the participants to start being physically active. However, friend and family support took precedence during the course of the intervention. To the researcher's knowledge there are very few studies that examine which social facilitators are required to maintain PA levels. In Brownson *et al.* (2001) social support from family and friends or program staff was established as one of the most definite determinants of PA.

In this study the aim was to examine what continued to motivate the participants to be physically active. Friends and family support was identified as the main facilitator. In South Africa this is very applicable, particularly in the Black and Coloured communities, where family support and encouragement carry a great deal of weight. The majority of the participants live with their families and extended families. This is what also makes the current study unique in that different cultures are represented, which is not the case in most literature.

Regardless of the type of support, support is important for people who acquire a permanent disability since there are many obstacles that prevent them from being physically active and being as independent as possible. In this study, most of the participants (14/16) said they had the support of their family and friends and they encouraged them to be physically active throughout the intervention. This is further supported by Brownson *et al.* (2001) who stated that a healthy community environment, together with social support, enable people to develop healthier lifestyles.

#### **5.7.4. Program/Policy Facilitators**

As mentioned in Chapter two, section 2.5.2, not many studies have investigated the program/policy facilitators. In the study done by The Life Group (2011), individually tailored programs and an exercise program that considers individual motivators to be facilitators were implemented. In the current study the greatest program/policy facilitators were good quality programs in the WCRC group. The second most important facilitator was related to staff, such as having skilled staff, enough staff and trained volunteers. In the

Community group, having enough trained volunteers and/or staff was what facilitated PA the most.

The quality of a program is irrelevant if there is not enough staff or volunteers available to run the program. However, without appropriate and tailored programs such as mentioned by The Life Group (2011), PA is also prevented. Although a good quality program was a facilitator in the beginning, trained volunteers and enough staff took precedence as the major facilitators over time. This was supported by the fact that the only facilitator that remained and encouraged continued participation was having enough staff or trained volunteers.

#### 5.7.5. **Conclusion**

Although the number of facilitators was reduced in this study, there was still a greater decrease in the number of barriers compared to the facilitators. This was expected since the aim of the intervention was to reduce the barriers as much as possible in order to facilitate PA behaviour. This is ideal, however, if the environment does not allow for PWaSCI to be physically active the personal facilitators will prove to be very ineffective and will result in low compliance to the recommended program. According to Suzuki, Krahn, McCarthy and Adams (2009) the environmental factors (physical, social and attitudinal aspects of the environment) can contribute either positively or negatively to the experience of the disability and health status of the person. The ICF of disability identifies environmental factors as anything that contributes to the disabling process (Suzuki, Krahn, McCarthy and Adams, 2007). This intervention program has therefore, proven to be successful in reducing and, to some extent, even eliminating some of the barriers previously identified, especially within the Community group. By providing volunteers with the appropriate training and equipment, PWaSCI are able to be physically active within their community. It is therefore, important that more community based health programs be put into place within different communities for PWaSCI to be physically active. This is of particular importance since rehabilitation services have declined and this decline ultimately affects the person's health (Rimmer and Henley, 2013). Most patients are therefore, expected to continue their recovery elsewhere. Often these programs are without ancillary services, which are needed to achieve good progress (Rimmer, 1999). This program has proven to bridge the gap that exists between rehabilitation and community based health and wellness.

## CHAPTER 6

### CONCLUSIONS AND RECOMMENDATIONS

#### 6.1. Introduction

This study set out to explore and identify the various barriers and facilitators that PWaSCI contend with in the process of being physically active. The study also sought to determine whether a reduction in these barriers could promote physical activity (PA) in a community based setting and contribute to each individual's health and wellness by improving the person's physical abilities and satisfaction with community participation. This research project was warranted as it was the researcher's opinion that a gap exists between in-patient rehabilitation and re-integration of people with a spinal cord injury (PWaSCI) into a physically active lifestyle within their communities. The following research questions guided the researcher in exploring this multifaceted issue:

1. What are the barriers to physical activity faced by PWaSCI?

Within a South African context, participating in PA is not straightforward, especially in PWaSCI. It was therefore, important to determine whether PWaSCI within South Africa face similar or additional barriers to PA. During Phase II of the study, an intervention programme was designed to effectively target these barriers, and to determine whether a community based PA program can have the same effect as PA program in a formal exercise setting.

The main findings in phase I of the study showed that although PWaSCI face similar barriers across the world, we do have barriers that are unique to South Africa. In this study, the barriers that seem to affect and pose the greatest challenge to PA were the environmental (40%) and program/policy barriers (33%). Similar results have been found by various researchers such as Rimmer, Riley, Wang, Rauworth and Jurkowski (2004) and Fekete and Rauch (2012). One of the main barriers found in developed countries were problems related to access. Within South Africa the main difference was the fact that the facilities catering for PWaSCI to be physically active are rare. Other environmental barriers included lack of adaptive equipment, lack of transport and the weather. Lack of transport seem to be a barrier that is synonymous worldwide. This barrier is exacerbated by the fact that within a developing country, public transport is in some cases not even an option due to lack of finances and infrastructure.

Program/policy barriers were the second most reported barriers in the current study, and proved to provide valuable insight into the current situation that PWaSCI face in terms of achieving health and wellness. In most cases PWaSCI have a desire to be active and they recognise the benefits of PA, however, lack of appropriate programs, cost of programs and lack of staff or trained volunteers, prevent PWaSCI from being physically active. Lack of trained volunteers is a barrier unique to developing countries. Due to the lack of healthcare professionals available, trained volunteers are a requirement to supplement certain initiatives and many organizations depend on volunteers for successful operation. However, in many cases volunteers are not available or properly trained to work with PWD. It is an important finding as PWaSCI feel insecure in the hands of volunteers that are not properly trained, which is consistent with the research found in developed countries with regards to staff competency.

Personal and social barriers were the least reported barriers in the current study. The main personal barriers identified, included secondary conditions, lack of finances, lack of skill and lack of knowledge. Secondary conditions and lack of finances are barriers faced across the world, however, lack of skill or knowledge about PA are barriers that are more unique to the developing world. Together with lack of information received about PA from therapist during inpatient rehabilitation (social barrier), the research identified a gap in education that exists amongst PWaSCI about personal health and wellness and the opportunity to be physically active. The current research might not be able to influence the education system, it does, however, provide important information for the people involved in in-patient rehabilitation in terms of educating their patients about the importance and possibility of being physically active post discharge.

It is clear from the diverse responses of PWaSCI that access to PA is a multifaceted issue and that South Africa is a long way off in breaking down the current barriers that PWaSCI face in attaining health and wellness. However, by identifying these barriers, awareness is created, which could help foster the process to health and wellness in this population.

2. Can a community based physical activity program, designed to reduce the previously identified barriers, help improve the physical abilities of PWaSCI? Furthermore, can a physical activity program work similar to a formal exercise setting in a community based setting?

This study was unique in that the focus was to reduce the barriers that PWaSCI face in being physically active and not merely to determine whether an exercise program can

improve the physical abilities of PWaSCI within a South African context. Most research focuses on either identifying the barriers or the impact an exercise program has on the physical abilities of PWaSCI. What makes this research even more unique is the fact that trained volunteers (initial barrier) were successful in running the program and this was indicated in the results, which showed that it was indeed possible for a community based setting to see improvements in the physical abilities and satisfaction with community reintegration of PWaSCI similarly to a formal exercise setting (WCRC group).

In both the WCRC (formal setting) and Community group there were continuous improvements in strength, power, flexibility and cardiovascular endurance and in the participants' satisfaction with community reintegration. Less significant differences were expected between the groups, but this could be explained by the lower initial fitness levels of the participants in the Community group and their injury levels. The participants from the Community group started with an overall lower fitness level and it took more time to see significant improvements in all the variables, but significant improvements took place, nonetheless. This was particularly evident in the percentage change that took place, over time. The Community group showed an overall greater percentage change over time from the baseline measurement than the WCRC group, in all the variables, except the one-stroke-push test. This possibly suggests that a community based PA can be successful in improving the physical abilities of PWaSCI, especially in people who start with a low fitness level due to lack of PA opportunities over a 16 week period.

There are various reasons that can explain the delay in significant improvements with injury level and residual muscle function being some of the most obvious problems. These reasons should also be taken into consideration when implementing PA programs within the community as it may ultimately affect motivation in some people due to the delay in experiencing the benefits of PA. Other possible reasons for the difference could be explained by the barriers that the people faced. This brings us to the final research question.

3. Did the perceived barriers to physical activity change after commencement of the intervention program? If so; were new barriers identified?

This part of the study was unique in that to the researcher's knowledge, no other study has evaluated the change in barriers over the course of an intervention. The intervention focused on reducing the main barriers that were identified in phase I of the study. This included the lack of finances, lack of skill/knowledge, lack of time, lack of accessible facilities and equipment, lack of information received, lack of appropriate programs and lack of trained



volunteers. During the course of the intervention, especially from pre to two months post, the above-named barriers were considerably reduced in both groups, but, especially in the Community group. This was anticipated, since the participants from the Community group initially identified more barriers and there were no PA opportunities available within their communities. During the intervention, the majority of the barriers were eliminated. However, during the course of the post-intervention period (from two to four months post) certain barriers reappeared and were mainly reported by the participants from the Community group. These barriers included lack of transport, the weather and lack of trained volunteers. Although lack of transport was reduced by 50% from information in the pre-intervention research questionnaire, it became a problem once again in the Community group during winter. One of the aims of implementing a community based program was that PWaSCI would not have to rely on transport to get to a facility. Although the facilities were a short travelling distance from the participant's place of residence, travelling in the cold and rain presented an obstacle. This is consistent with the literature in that precipitation is one of the main correlates that negatively impacts PA (Chan and Ryan, 2009). Thus, lack of transport resurfaced as a barrier. With the change in seasons from autumn to winter, the weather also became an increasing concern and barrier to PA participation, especially in the Community group. Although these barriers reappeared with the change in seasons, it did not give rise to PA termination, but only meant that the participants could not attend all the sessions in the post-intervention period. This information supports the literature in that certain weather conditions affect PA participation and this information can help policy makers or healthcare providers mitigate its effects, by providing alternatives during those seasons such as providing home based programs.

As mentioned in the methodology section, the Community group was divided into two environments, namely, Strand and Macassar. In one of the environments lack of volunteers were not a barrier, however, in the other environment lack of trained volunteers became a barrier. Although PA did not cease within the group, more volunteers were needed in order to run the PA program and to prevent lack of trained volunteers from becoming a reason for PA termination.

The weather and lack of trained volunteers are barriers that, to an extent, are beyond the researcher's control. The weather conditions cannot be changed, however, its effects mitigated and people cannot be persuaded to do something they do not want to do or cannot do due to personal reasons or circumstances. However, volunteer recruitment and training should be a continuous process to ensure the success of a community based PA program. The program has also shown that the best volunteers are those who are already committed

to assisting a friend or family member with a SCI and that experience the benefits of PA first hand.

Regardless of the barriers, many facilitators were also identified by the participants and they are important to consider in subsequent continued participation. The facilitators that stood out the most were that PA made the participants feel good, gave them a desire to be physically active, the accessible and safe location of facilities, friend and family support and lastly, having enough staff or trained volunteers. In the study, the friend and family support was reported by all but two of the participants as important, the latter saying that support from peers was more important to them. Regardless of the type of support, support is important and according to Brownson *et al.* (2001) one of the most clear determinants of PA.

As mentioned earlier, PA is necessary for improving and maintaining optimum functioning and health and this was illustrated in the study as the participants improved their physical abilities and community reintegration scores. Regardless of the barriers that remained, they were still considerably reduced and all 16 participants committed to staying physically active. The main reasons for wanting to stay physically active were, because the participants experienced the benefits of PA, saw improvements and had a taste of health and wellness. Health and wellness are not achieved in a short intervention, but by adopting a physically active lifestyle. According to Leventhal and Leventhal (2000) (in Putnam *et al.*, 2003) PWD and those without disabilities, perceive health as a complex multi-dimensional concept. In their definition, physical health is not the only variable. Also being able to do what they desire and, at the same time having a general feeling of well-being. This was emphasized in the current research, where one participant said “his well-being was a reason to stay physically active” and yet another that “he was able to do more for himself and that he even ate better.” Another participant said that “he would continue as he wanted to help himself more and lose weight.” In the WCRC group, one participant also said that it “helped him to be more mobile” and another participant that “being active was in his blood.” Other participants also said they would continue to be physically active as it “improved their confidence and fostered self-respect.” This illustrates that PA is more than just being free from secondary conditions or complications, but that it also fosters independence. Hence, PA has the potential to influence and contribute to other aspects of life as well. This is reiterated by Kerstin *et al.* (2006) that PA has the potential for a person to become as independent as possible, thereby avoiding assistance in ADL as much as possible.

Furthermore, in the current study a participant from the WCRC group said that “gaining independence was important and a reason to stay PA.” The majority of the participants also mentioned that they “would continue to be physically active in order to stay fit, maintain fitness and their weight” and “to generally improve their health.” This gives the perception that the participants have noticed a change in their physical and mental abilities and would like to maintain and even improve on these aspects of their lives. From these responses, it is evident that the participants have experienced the various benefits of PA. It is also clear that the above-mentioned reasons are all personal facilitators that can motivate PWaSCI to continue to be physically active and achieve health and wellness.

The results in this study have contributed to the already existing body of knowledge regarding the barriers and facilitators that PWaSCI face in being physically active in a developing country. This information will hopefully assist policy makers in identifying the “problem areas” and lead to change. The results also showed that by following the Rec Tech RAMP model in removing the identified barriers in terms of access to PA as well as by encouraging participation and adherence that the participants were on their way to improved health and function.

## **6.2. Conclusion**

To the researcher’s knowledge, this was one of the first interventions that was implemented in a community based setting that not only measured physical improvements of the participants, but also monitored the change in barriers that affected PA participation over time. It is imperative that the knowledge gained from this study be used to further implement community based PA programs to supplement the work of healthcare professionals, by bridging the gap between in-patient rehabilitation and community based health and wellness. After all, surely all human beings are entitled to health and wellness and basic human rights such as being physically active. Not only will PA help reduce the occurrence of secondary conditions and medical conditions within this population, but it will also help reduce the number of rehospitalisations which will indirectly reduce the economic burden. Physical activity is essential in ensuring an improved QOL and independence within this marginalized population and should therefore become a public health priority. The research has shown that by identifying the relevant barriers and targeting these barriers a community based PA program can indeed achieve success similar and even greater than that of a formal exercise setting.

### 6.3. Summary of Practical Implications

Over the course of the last three years a lot of time and effort was spent on researching the barriers and facilitators that PWD, and more specifically PWaSCI face in terms of being physically active, and how to overcome these barriers through PA. Researchers, have used different methods in collecting the relevant information specific to their country and study population. Some of these methods included semi-structured interviews (Conchar *et al.*, 2014), surveys (Scelza *et al.*, 2005), questionnaires (Jaarsma, *et al.*, 2014) and focus groups (Rimmer *et al.*, 2004). Regardless of the method of data collection, the importance for the practitioner is the identification of the relevant barriers and facilitators that are specific to the population's needs and targeting those barriers to facilitate health and wellness within the population.

In summary:

- Identify what motivates the individual and group to remain physically active
- Keep the volunteers motivated and make sure they are appreciated and experience the benefits of PA themselves. By doing so they are able to help recruit new participants for the group and motivate the participants to keep coming
- Provide ongoing training and education to the volunteers and the participants where needed and possible
- Always keep recruiting volunteers that can assist to run programs
- The best volunteers are those directly involved with individuals with a SCI, such as family members, care givers and friends
- Be involved as much as possible as a health care practitioner in terms of following up with volunteers, updating programs and providing additional equipment where possible
- Show appreciation to the companies/organizations/individuals that provide training venues every week

### 6.4. Limitations to the Study

The results of this study have to be interpreted in the light of its limitations. The limitations for Phase I was the small number of participants that completed the research questionnaire. The research questionnaire was also only completed by individuals living within the Western Cape Province. PWaSCI living in other parts of the country may therefore face additional or other barriers and would need alternative or specific interventions for those. Although a limitation, it was important to gather data relevant to the Western Cape as the intervention took place in the Western Cape. The results of the research questionnaire can therefore not

be generalized to the larger population of South Africa. Another limitation was that the research questionnaire was not validated.

Another limitation related to Phase I of the study was that the participants were not asked when their injury occurred on the research questionnaire? During the design of the questionnaire this information did not seem relevant (wanted to know their current situation), however, in retrospect this may possibly have impacted the barriers and facilitators as well as the physical testing. It is recommended to add this in future research studies.

The first limitation also applies to the small intervention sample in Phase II of the study. Only 16 participants partook in the intervention. Possible reasons for the small sample size were that participants had to have no secondary conditions/co-morbidities and had to be able to manually propel a wheelchair. These factors reduced the sample size considerably. These criteria were set in order to ensure the safety of the participants. Although the sample size was small, various lesion levels were represented, as well as the dominant races within the Western Cape. The results can, however, once again not be generalised to a larger population in South Africa. Another limitation was the location of the intervention in phase II. A sample of convenience was chosen at all three environments, instead of a random sample. Already established contacts within these communities were used, since it is difficult to locate PWaSCI once they are discharged from hospital, due to the lack of SCI databases in South Africa. Unless PWaSCI are involved in a community project or support group they are difficult to locate and due to confidentiality issues their information could also not be obtained from hospital personnel. The results can therefore not be generalised to a larger population in South Africa.

Although not an objective of the study, but a limitation nonetheless, was that some of the physical tests and the RNLI was not tested for validity and reliability for the current population. Although all the tests have been tested for validity and reliability in PWaSCI, two of the tests were modified to suit the community and the scarce resources found in these communities. The results of these tests possibly do not correlate with the original normative data, but the test results were only used to compare the pre and post testing and to demonstrate whether the participants within the Community group could improve similarly to the participants from the WCRC group. The intention was therefore not to interpret levels of fitness in comparison to other studies.

## 6.5. Recommendations for Future Research

With regard to the limitations of the current research, there are a number of unexplored areas for future research. As demonstrated, PA for PWaSCI is a multifaceted issue and further research needs to be conducted in order to understand the predictors of PA participation (Tawashy *et al.*, 2009) and continued participation. Firstly, the study needs to be replicated in a larger and more diverse sample. This includes PWaSCI from all nine provinces within South Africa. Subsequent to the proposed expanded study, the design of a national intervention should be tailored to the specific needs of PWaSCI and implemented within different communities in order to determine what is required for community based health and wellness. Future research is therefore, also encouraged to better understand the change in barriers that take place once an intervention has been implemented and to determine whether a community based PA program is sustainable over a longer period of time (12 months). A better understanding is required for the development and implementation of PA programs promoting health and wellness within PWaSCI. Furthermore, the study can be replicated in other groups of people who have acquired a disability. Research in identifying the barriers and facilitators that volunteers face in staying actively involved in the community can also be another area of focus. This will also lead to a better understanding of the successes and failures of community based interventions. This study has shown that community based programs is possible and future research can therefore focus on the process of including PWD in already established community based health initiatives, to foster a more inclusive society. Lastly, future research is required in the quantitative methods. This includes testing for the validity and reliability of the two tests that were modified in PWaSCI and whether they correlate with the current standards of the tests.

The focus of this study was to identify and reduce the barriers that PWaSCI face in being physically active through a community based physical activity program. The research provides initial support that a community based PA program can, indeed improve the physical abilities of PWaSCI, increase their satisfaction with community reintegration and reduce the barriers that PWaSCI face when being physically active. Program attendance is however, influenced by the number of trained volunteers available to assist the participants and also, the weather where own or public transport is not an option. By taking all of the above into consideration, creating more PA opportunities for PWaSCI is possible and will be the starting point of a journey towards health and wellness within many marginalized groups.

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## APPENDIX A: RESEARCH QUESTIONNAIRE



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jou kennisvennoot • your knowledge partner

### BRIDGING THE GAP FROM INPATIENT REHABILITATION TO SUSTAINABLE HEALTH AND WELLNESS IN SPINAL CORD INJURED INDIVIDUALS

#### Research Questionnaire for Participants

##### Definitions:

**Physical Activity (PA):** Any bodily movement produced by the contraction of skeletal muscles that result in a substantial increase over resting energy expenditure (RER).

**Exercise:** A type of physical activity consisting of planned, structured and repetitive bodily movement done to improve or maintain one or more components of physical fitness.

**Personal History:** Please fill in your information in below

#### 1. Personal information

Name and Surname: [Click here to enter text.](#)  
Date of birth: [Click here to enter text.](#)  
Ethnicity: [Click here to enter text.](#)  
Gender: [Click here to enter text.](#)  
Contact details: [Click here to enter text.](#)

**Please tick the applicable boxes below (You are able to tick more than one)**

#### 2. Current medical conditions/ Secondary conditions

- Diabetes
- Heart condition/Cardiac diseases
- High blood pressure
- Cholesterol problems
- Pressure sores
- Chronic bladder infection
- Other (please specify below)  
[Click here to enter text.](#)

#### Part I: Experience prior to injury

##### 3. Did you participate in any physical activity before your injury?

- Yes
- No

##### 4. If yes what is your experience with physical activity prior to injury

###### a. Type of physical activity

- Individual or team sport

- Cardiovascular: Running/cycling/swimming/rowing
- Strength: Weight training/circuit training/home gym
- Flexibility: Stretching/Yoga/Pilates
- Recreational activities (Hiking, bowels etc)
- Other (please specify below)

[Click here to enter text.](#)

**b. Duration of physical activity**

- < 30min/session
- 30-60min/session
- 60-90min/session
- >90min/session

**c. Intensity of physical activity**

- Light: walking slowly around home/store; washing dishes; playing cards
- Moderate: walking at brisk pace; washing windows, sweeping floors, carrying/stacking wood; bicycling, ballroom dancing, table tennis
- Vigorous: jogging/running; shoveling sand, carrying heavy loads (bricks); soccer, bicycling on moderate effort or fast

**5. Why did you exercise?**

- Always been involved in sport from a young age
- Healthy lifestyle/benefits of exercise
- Social aspect
- Family and friends support
- Advised by doctor/ because of other medical conditions
- Other (please specify below)

**6. If you did not participate in physical activity before your injury what was your reason/s?**

- Lack of time
- Lack of money
- Lack of knowledge
- Lack of opportunities
- Lack of motivation/willingness
- Other (please specify below)

[Click here to enter text.](#)

**7. Were you aware of disability sports before your injury?**

- Yes
- No

**Pat II: Inpatient rehabilitation/Hospitalisation**

**8. Injury and initial hospitalisation**

**a. How did your injury occur?**

- Motor vehicle accident (MVA)

- Violence
- Gunshot or Stab
- Diving or sporting accident
- Disease
  - a. Tb spine
  - b. Cancer
  - c. Other (please specify below)  
[Click here to enter text.](#)
- Other (please specify below)  
[Click here to enter text.](#)

**b. Where were you hospitalized?**

- The Eastern Cape
- The Free State
- Gauteng
- KwaZulu-Natal
- Limpopo
- Mpumalanga
- The Northern Cape
- North West
- The Western Cape

**c. What type of hospital were you admitted?**

- Private
- Government

**d. How long were you hospitalised?**

- <3 months
- 3-6 months
- >6 months

**e. What type of inpatient treatment did you receive?**

- Physiotherapy
- Occupational therapy
- Social worker
- Psychologist
- Biokineticist/Health and Wellness practitioner
- Other (please specify below)  
[Click here to enter text.](#)

**f. How many hours per day did you receive therapy?**

- |  |  |
|--|--|
| <input type="checkbox"/> 1 day per week    | <input type="checkbox"/> 1 hour per day    |
| <input type="checkbox"/> 2-3 days per week | <input type="checkbox"/> 2-3 hours per day |
| <input type="checkbox"/> 3-5 days per week | <input type="checkbox"/> 3-5 hours per day |

**g. Upon discharge did you feel confident to go home and return to your**

**community?**

- Yes
- No
- Somewhat

If no what did you struggle with?

[Click here to enter text.](#)

**h. Were you exposed or informed about to Physical Activity/Health and wellness during inpatient care?**

- Yes
- No

**i. If so during what phase were you informed?**

- Early phase/after you were medically stable
- Mid phase/during your therapy sessions with OT/PT/Social worker
- Late phase/at the end before discharge

**j. Did you receive information about sports for persons with disabilities?**

- Yes
- No

**k. If so during what phase were you informed?**

- Early phase/after you were medically stable
- Mid phase/during your therapy sessions with OT/PT/Social worker
- Late phase/at the end before discharge

**Pat III: Current Information**

**9. Number of hospitalisation in the last year and reasons for hospitalisation?**

- |                              |   |
|------------------------------|---|
| <input type="checkbox"/> 1-3 | <input type="checkbox"/> Bladder infection (UTI)      |
| <input type="checkbox"/> 4-6 | <input type="checkbox"/> Pressure sores               |
| <input type="checkbox"/> >6  | <input type="checkbox"/> Ulcers (Skin disorders)      |
|                              | <input type="checkbox"/> Respiratory conditions       |
|                              | <input type="checkbox"/> Other (please specify below) |

[Click here to enter text.](#)

**10. Number of hospitalisations in the last three years and reasons for hospitalisation?**

- |                              |   |
|------------------------------|---|
| <input type="checkbox"/> 1-3 | <input type="checkbox"/> Bladder infection (UTI)      |
| <input type="checkbox"/> 4-6 | <input type="checkbox"/> Pressure sores               |
| <input type="checkbox"/> >6  | <input type="checkbox"/> Ulcers (Skin disorders)      |
|                              | <input type="checkbox"/> Respiratory conditions       |
|                              | <input type="checkbox"/> Other (please specify below) |

[Click here to enter text.](#)

**11. Are you aware of physical activity?**

- Yes
- No
- Somewhat

**12. How did you hear about physical activity?**

- Inpatient Rehabilitation
- a. Physiotherapy
  - b. Occupational Therapy
  - c. Doctor
  - d. Other (please specify below)

[Click here to enter text.](#)

- Out patient
  - Peers with SCI
  - Family
- Media
- a. Internet
  - b. TV
  - c. Pamphlets/brochures
  - d. Other

**13. Do you currently participate in physical activity?**

- Yes
- No

**14. When did you start with physical activity?**

- Immediately after discharge (within first year)
- 1-3 years after discharge
- >3 years after discharge

**If you answered yes to question 13, please complete question 15. If you answered no to question 13, please go straight to answering question 16.**

**15. What is your experience with physical activity post injury?**

**a. What type of physical activity do you do?**

- Individual / team sport
- Cardiovascular: Running/cycling/swimming/rowing
- Strength: Weight training/circuit training/home gym
- Flexibility: Stretching/Yoga/Pilates

**b. How long do you do physical activity?**

- < 30min/session
- 30-60min/session
- 60-90min/session



>90min/session

**c. At what intensity level do you do physical activity?**

Light: walking slowly around home/store; washing dishes; playing cards

Moderate: walking at brisk pace; washing windows, sweeping floors, carrying/stacking wood; bicycling, ballroom dancing, table tennis

Vigorous: jogging/running; shoveling sand, carrying heavy loads (bricks); soccer, bicycling on moderate effort or fast

**16. What barriers do you currently experience that prevent you from exercising?**

**Personal**

Lesion level

a. Quadriplegic

b. Paraplegic

Secondary conditions

a. Pressure sores

b. Ulcers

c. Bladder infections

d. Other (please specify below)

[Click here to enter text.](#)

b. Lack of finances

c. Pain

d. Lack of skill/fitness

e. Lack of knowledge or awareness about physical activity

f. Lack of time

g. Other (please specify below)

[Click here to enter text.](#)

**Social**

a. Lack of family/friend support

b. Negative societal attitudes

c. Lack of role models

d. Lack of information received during inpatient rehabilitation

e. Other

**Environmental**

a. Lack of facilities

b. Inaccessible facilities

- c. Inconvenient location of facilities/physical obstacles to reach facilities
- d. No space to be physically activity
- e. Lack of adaptive equipment
- f. Lack of transport
- g. Weather
- h. Other (please specify below)

[Click here to enter text.](#)

#### **Program/Policy Barriers**

- a. Lack of appropriate programs
- b. Lack of inclusive programs
- c. Cost of programs
- d. Lack of staff capacity/training/experience
- e. Lack of trained volunteers
- f. Lack of guidance by staff
- g. Negative attitudes of staff
- h. Other (please specify below)

[Click here to enter text.](#)

#### **17. If you are physically active what facilitators help you to physical activity?**

##### **Personal**

- a. Desire to be active/fit
- b. Improve self confidence/self esteem
- c. Feel good/enjoyable
- d. Other (please specify below)

[Click here to enter text.](#)

##### **Social**

- a. Family/friend support
- b. Positive encouragement from peers with disabilities
- c. Positive societal attitudes
- d. Role models
- e. Adequate information from OT/PT from inpatient rehabilitation

f. Other (please specify below)

[Click here to enter text.](#)

**Environmental**

- a. Accessible facilities
- b. New facilities in rural areas
- c. Transport
- d. Safe locations of facilities
- e. Other

**Program/Policy Barriers**

- More and better quality programs
- Skilled staff
- Trained volunteers
- Enough staff
- Other (please specify below)

[Click here to enter text.](#)

**18. What do you think are the benefits of being physically active?**

- Improved self esteem/self confidence
- Improved quality of life
- Assists with the completion of Activities of Daily Living with more ease
- Less fatigue
- Less pain
- Prevention of secondary conditions such as diabetes, cardiac conditions, high blood pressure etc.

**19. What do you think are the consequences of being physically active?**

- Fatigue
- Muscle pain
- Less time with family/friends
- Worsens the condition
- Other

**20. Do you have future plans of becoming or staying physically active?**

- Yes
- No

**21. What would you like to see in a physical activity program? (please specify below)**

[Click here to enter text.](#)

**22. Are you aware of sports for persons with disabilities?**

- Yes
- No

**23. If yes, how did you hear about sports for persons with disabilities? (please specify below)**

[Click here to enter](#)

## APPENDIX B: INFORMED CONSENT



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvennoot • your knowledge partner

### STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

---

Bridging the Gap from Inpatient Rehabilitation to Sustainable Health and Wellness in Spinal Cord Injured Individuals

You are asked to participate in a research study conducted by C. Vermaak, MPhil APA, from the Sport Science Department at Stellenbosch University. The results of the study will contribute to a PhD dissertation. You were selected as a possible participant in this study because you have a spinal cord injury (SCI).

#### 1. PURPOSE OF THE STUDY

This study aims to bridge the gap between inpatient rehabilitation and reintegration to active living through a physical activity program. Bridging gap means identifying the barriers faced by persons with a SCI that prevents them from living an active and healthy lifestyle. Reintegration is related to the functional status (what the person can physically do) of the individual. Reintegration also means that the person can function and be independent. This does not mean the individual is free from disease or disability but that reintegration is aimed at the relief of discomfort caused by the disability and improving the person's abilities (what they can do). Reintegration contributes to health. Health has a direct link to physical activity. Thus attaining health is an ultimate end goal of the physical activity program.

#### 2. PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

##### Part I: Questionnaire

Complete the questionnaire and return it to the respective agent either electronically, personally or via mail. If you do not wish to answer any of the questions included in the questionnaire, you may skip them and move on to the next question. After completion of the questionnaire, you will receive information about the intervention part of this study. The choice is yours to either volunteer for the rest of the study, or to decline the invitation.

## Part II: Intervention

If you volunteer to participate in the intervention, you will be asked to attend two exercise sessions per week for 12 consecutive weeks. The intervention will be based on the health components of physical activity and will involve endurance, strength and functional exercises. You will also complete a few simple exercise tests before and after the intervention to assess changes in your physical abilities. You will also be asked to complete the Return to Normal Living Index questionnaire pre and post the intervention. Before the intervention you will be screened to make sure that it is safe for you to partake in physical activity. This screening will be done by completing a PAR Q AND YOU Questionnaire. If you are classified as high risk, you will be asked to obtain medical clearance from your doctor that you are able to partake in physical activity and that it is safe for you to do so. The clearance will however be at your own cost. You will also only be included in the study if you meet the following criteria below:

### Inclusion criteria

Participants will be included in the study if they meet the following criteria:

1. Aged between 18-65 years
2. Have completed the PAR Q and YOU health questionnaire
3. Have:
  - a. A SCI below and including C5 neurological level of injury (ASIA Classification Scale A-D)
  - b. Paraplegia
  - c. Quadriplegia
4. Speak English, Afrikaans or Xhosa
5. According to American College of Sports Medicine (ACSM) have only one risk factor.
6. According to ACSM guidelines have more than 1 risk factor, but are cleared by a physician to participate.
7. Able to manually propel a wheelchair.

### Exclusion criteria

Participants will be excluded from the study if they have:

1. Cardiovascular contraindications for exercise.
  - a. A recent significant change in the resting ECG suggesting significant ischemia, recent myocardial infarction (within 2 days) or other acute cardiac event
  - b. Unstable angina

- c. Uncontrolled cardiac dysrhythmias causing symptoms or hemodynamic compromise
  - d. Symptomatic severe aortic stenosis
  - e. Uncontrolled symptomatic heart failure
  - f. Acute pulmonary embolus or pulmonary infarction
  - g. Acute myocarditis or pericarditis
  - h. Suspected or known dissecting aneurysm
  - i. Acute systematic infection, accompanied by fever, body aches, or swollen lymph glands
2. Additional co-morbidities that will affect response to exercise such as diabetes.
  3. A resting systolic BP >180mmHg and a resting diastolic BP >90mmHg
  4. Compromising complaints of the musculoskeletal system e.g. current shoulder injury.
  5. Have pressure sores and/or a bladder infection.
  6. Missed four consecutive exercise sessions or more than six sporadic sessions.

### **3. POTENTIAL RISKS AND DISCOMFORTS**

#### **Part I: Questionnaire**

During this part of the study there are no physical risks involved.

#### **Part II: Intervention**

The methods and equipment that will be used during the study pose no physical risks other than the usual risks associated with exercise testing and exercise. Some of the risks include:

- Fatigue after an exercise test or exercise session
- Muscle strain
- Joint pain

All efforts will be made to ensure that the exercises are done in a safe manner and a safe environment. Individuals who will supervise the exercise sessions are suitably trained to ensure your safety and wellbeing.

### **4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

#### **Part I: Questionnaire**

There will be no direct benefit to you, but your participation is likely to help us find out more about how to improve sustainable health and wellness in persons living with a SCI and to improve the quality of life through physical activity.

#### **Part II: Intervention**

The benefits of physical activity are well known and include: improved functional capacity, endurance, muscle strength, psychological well being as well as the reduction of stress. You will also receive feedback in the form of a report at the end of the study indicating your progress and achievements.

## **5. PAYMENT FOR PARTICIPATION**

As a participant in this study, you will not receive any remuneration for your participation.

## **6. CONFIDENTIALITY**

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of allocating a number to your name. All hard copies will be scanned and saved in a password protected file. Also the hard copies will be stored at the Sport Science Department in a locked room. Access will only be granted to the principle investigator and promoters. Published information will not reveal any names or any information that can link the results directly to you. .

## **7. PARTICIPATION AND WITHDRAWAL**

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

## **8. IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about the research, please feel free to contact:

Candace Vermaak

Dr. S. Ferreira

Prof. E, Terblanche

E: 14076454@sun.ac.za

E: sferreira@sun.ac.za

E: et2@sun.ac.za

C: 0827821625

C: 0824981712

C: 0827076501

## **9. RIGHTS OF RESEARCH SUBJECTS**

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.



**SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE**

The information above was described to *me* by Candace Vermaak in *Afrikaans/English* and I am in command of this language or it was satisfactorily translated to me. *I* was given the opportunity to ask questions and these questions were answered to my satisfaction.

*I hereby consent voluntarily to participate in this study* I have been given a copy of this form.

\_\_\_\_\_  
Name of Subject/Participant

\_\_\_\_\_  
**Name of Legal Representative (if applicable)**

\_\_\_\_\_  
Signature of Subject/Participant or Legal Representative

\_\_\_\_\_  
Date

**SIGNATURE OF INVESTIGATOR**

I declare that I explained the information given in this document to \_\_\_\_\_.  
*He/she* was encouraged and given ample time to ask me any questions. This conversation was conducted in *Afrikaans/\*English/\*Xhosa/* and *no translator was used/this conversation was translated into \_\_\_\_\_* by \_\_\_\_\_.

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Date

## APPENDIX C: PHYSICAL ACTIVITY READINESS QUESTIONNAIRE (PAR Q AND YOU)

This PAR-Q "Physical Activity Readiness Questionnaire" is for your personal use only. It does not need to be signed and returned to SBCC. Please read the questions carefully, answer them honestly, and consider the recommendations for your personal safety. Thank You!

### PAR-Q & YOU

(A Questionnaire for People Aged 15 to 69)

Regular physical activity is fun and healthy, and increasingly more people are starting to become more active every day. Being more active is very safe for most people. However, some people should check with their doctor before starting to become much more physically active.

If you are planning to become much more physically active than you are now, start by answering the seven questions in the box below. If you are between the ages of 15 and 69, the PAR-Q will tell you if you should check with your doctor before you start. If you are over 69 years of age, and you are not used to being very active, check with your doctor.

Common sense is your best guide when you answer these questions. Please read the questions carefully and answer each one honestly: check YES or NO.

YES	NO	
<input type="checkbox"/>	<input type="checkbox"/>	1. Has your doctor ever said that you have a heart condition <u>and</u> that you should only do physical activity recommended by your doctor?
<input type="checkbox"/>	<input type="checkbox"/>	2. Do you feel pain in your chest when you do physical activity?
<input type="checkbox"/>	<input type="checkbox"/>	3. In the past month, have you had chest pain when you were not doing physical activity?
<input type="checkbox"/>	<input type="checkbox"/>	4. Do you lose your balance because of dizziness or do you ever lose consciousness?
<input type="checkbox"/>	<input type="checkbox"/>	5. Do you have a bone or joint problem (for example, back, knee or hip) that could be made worse by a change in your physical activity?
<input type="checkbox"/>	<input type="checkbox"/>	6. Is your doctor currently prescribing drugs (for example, water pills) for your blood pressure or heart condition?
<input type="checkbox"/>	<input type="checkbox"/>	7. Do you know of <u>any other reason</u> why you should not do physical activity?

**If you answered**

#### YES to one or more questions

Talk to your doctor by phone or in person BEFORE you start becoming much more physically active or BEFORE you have a fitness appraisal. Tell your doctor about the PAR-Q and which questions you answered YES.

- You may be able to do any activity you want – as long as you start slowly and build up gradually. Or, you may need to restrict your activities to those which are safe for you. Talk with your doctor about the kinds of activities you wish to participate in and follow his/her advice.
- Find out which community programs are safe and helpful to you.

#### NO to all questions

If you answered NO honestly to all PAR-Q questions, you can be reasonably sure that you can:

- start becoming much more physically active – begin slowly and build up gradually. This is the safest and easiest way to go.
- Take part in a fitness appraisal – this is an excellent way to determine your basic fitness so that you can plan the best way for you to live actively. It is also highly recommended that you have your blood pressure evaluated. If your reading is over 144/94, talk with your doctor before you start becoming much more physically active.

#### DELAY BECOMING MUCH MORE ACTIVE:

- If you are not feeling well because of a temporary illness such as a cold or a fever – wait until you feel better; or
- If you are or may be pregnant – talk to your doctor before you start becoming more active.

**PLEASE NOTE:** If your health changes so that you then answer YES to any of the above questions, tell your fitness or health professional. Ask whether you should change your physical activity plan.

**Informed use of the PAR-Q:** The Canadian Society for Exercise Physiology, Health Canada, and their agents assume no liability for persons who undertake physical activity, and if in doubt after completing this questionnaire, consult your doctor prior to physical activity.

No changes permitted. You are encouraged to photocopy the PAR-Q but only if you use the entire form.

NOTE: If the PAR-Q is being given to a person before he or she participates in a physical activity program or a fitness appraisal, this section may be used for legal or administrative purposes.

"I have read, understood and completed this questionnaire. Any questions I had were answered to my full satisfaction."

NAME \_\_\_\_\_

SIGNATURE \_\_\_\_\_

DATE \_\_\_\_\_

SIGNATURE OF PARENT \_\_\_\_\_

WITNESS \_\_\_\_\_

Or GUARDIAN (for participants under the age of majority)

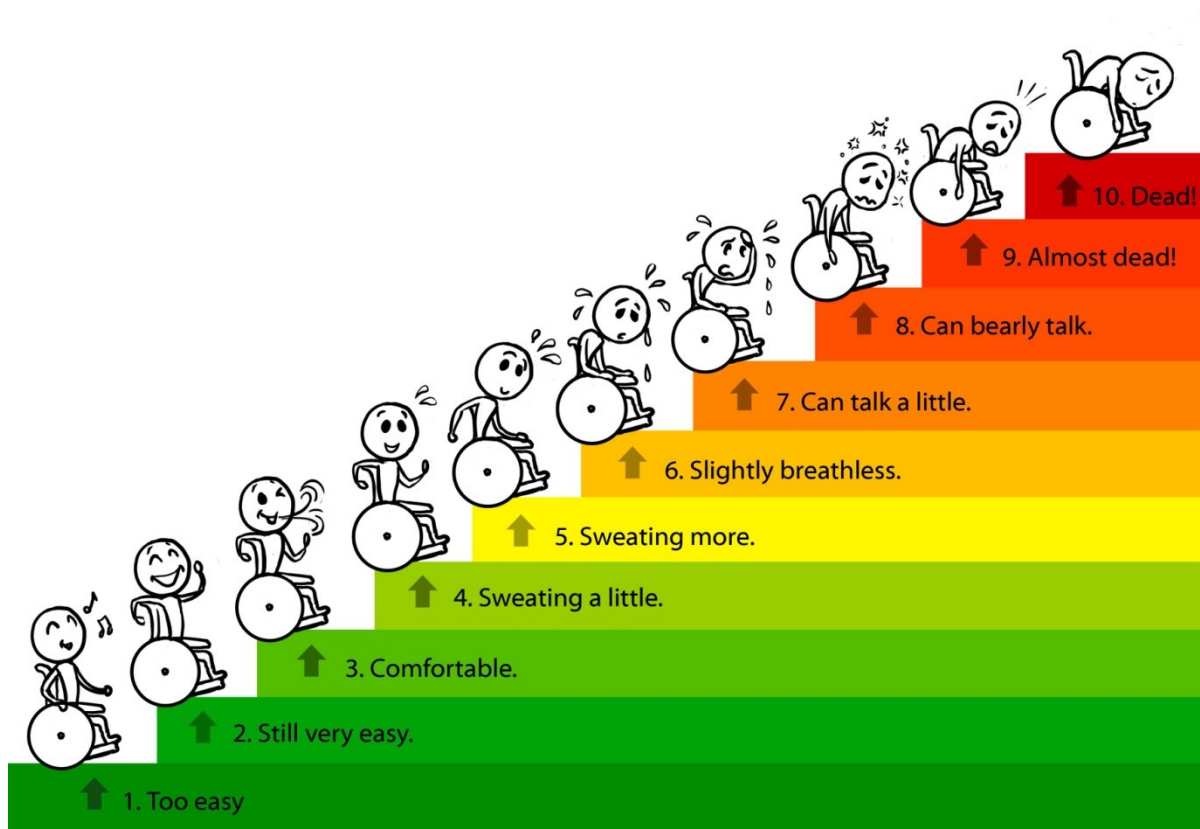
Note: This physical activity clearance is valid for a maximum of 12 months from the date it is completed and becomes invalid if your condition changes so that you would answer YES to any of the seven questions.

### REFERENCE

Canadian Society for Exercise Physiology. (2002). *PAR-Q & YOU*. [Online] Available at <http://www.csep.ca/cmfiles/publications/parq/par-q.pdf> ACSM. (Accessed 12th May 2016)

## APPENDIX D: BORG RATE OF PERCEIVED EXERTION (RPE)

The Borg Scale is a simple method of rating perceived exertion (RPE) and is used as a valuable indicator for measuring a person's exercise tolerance (ACSM, 2013). It allows the exerciser to subjectively rate his/her feelings during exercise taking the following into account; personal fitness level, environmental conditions and general fatigue levels. The rating may be influenced by the following: psychological factors, mood states, environmental conditions, exercise modes and age. The category ration scale will be used in the study and is seen below.



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## APPENDIX E: 12 MIN PUSH TEST

### AIM

To determine cardiovascular capacity.

**Table 1: Criteria for administering 12min-push test**

Equipment	Procedure	Scoring
1. 400m running track	1. Place markers at set intervals around the track (e.g. every 50m) to aid in measuring the completed distance.	1. Record the completed distance to the nearest 100 meters.
2. Measuring tape	2. Participants wheel around the track for 12minutes and the distance covered is recorded.	
3. Recording sheets	3. The participants must be encouraged to push themselves as hard as they can.	

**Table 2: Guidelines for interpreting test results**

Rating	Distance (miles)	Distance (meters)	Estim. VO <sub>2</sub> max (ml/kg/min)
Excellent	>1.59	> 2560	> 36.2
Above average	1.36-1.59	2171 - 2560	29.2 - 36.2
Average	0.87-1.35	1381 - 2170	14.6 - 29.1
Below average	0.63-0.86	1010 - 1380	7.7 - 14.5
Poor	<0.63	< 1010	<7.7

### VALIDITY

Not established.

### RELIABILITY

Depends on practice, pacing and motivation. If these are addressed there is a good reliability.

## REFERENCE

Vanderthommen, M., Francaux, M., Colinet, C., Lehance, C., Lhermerout, C., Crielaard, J-M.D. Theisen (2002). A multistage field test of wheelchair users for evaluation of fitness and prediction of peak oxygen consumption, *Journal of Rehabilitation Research and Development*, 39(6):685-692.

## **APPENDIX F: ONE STROKE PUSH TASK**

### **AIM**

To test functional ability in an everyday common task that requires strong effective propulsion.

### **EQUIPMENT**

- 1.5m carpeted surface
- Measuring tape

### **PROCEDURE**

With all 4 wheels positioned on the carpeted surface (1.5-cm pile), the participant propelled the wheelchair forward by pushing once with maximal effort. Hand placement to begin propulsion was at the discretion of the participant. The most posterior point of the rear wheels was marked as the starting point (a meter stick with a carpenter's level was used to ensure accuracy). Once the wheelchair rolled to a stop, the most posterior point of the rear wheels was marked to indicate the completed distance pushed. If the push was asymmetrical, the mark was recorded for the most posterior rear wheel. The distance (cm) between the 2 marked points was recorded. Back supports may improve trunk extension and subsequently allow greater shoulder extension, so that the position of the hand toward the apex of the wheel could enable the user to achieve increased distance per stroke.

### **SCORING**

This test is scored in cm.

### **VALIDITY**

No values are reported for the validity of the 4FTPSMW for the SCI population.

### **RELIABILITY**

Test-retest reliability is excellent ( $r = 0.99$ )

### **REFERENCE**

May, L.A., Butt, C., Minor, L., Kolbinson, K. and Tulloch, K. (2003). Measurement Reliability of Functional Tasks for Persons Who Self-Propel a Manual Wheelchair. *Archives of Physical Medicine and Rehabilitation*, 84: 578-583.

## **APPENDIX G: FORWARD VERTICAL REACH TEST**

### **AIM**

To test functional ability in an everyday common task that requires lifting of upper extremities.

### **EQUIPMENT**

- 1m measuring stick
- Felt pen

### **PROCEDURE**

The wheelchair was positioned parallel to the marking board, and participants held the measuring stick, independently or with cuff supports, using both hands (palms down). The 1-m measuring stick had a felt pen attached to one end and a carpenter's level secured in the middle. The tip of the felt pen was positioned within 2.54cm (1in) of the marking board. Participants began with forearms parallel to their thighs and raised the measuring stick upward. Participants were instructed to keep the measuring stick level and to avoid excessive backward arching. A dot was made with the felt pen on the marking board at the highest point reached. The distance in centimeters from the floor to the dot was measured. Bilateral reach was selected as a better test of the stability provided by the back support than unilateral reach.

### **SCORING**

This test is scored in cm.

### **VALIDITY**

No values are reported for the validity of the 4FTPSMW for the SCI population.

### **RELIABILITY**

Test-retest reliability is excellent ( $r = 0.99$ )

### **REFERENCE**

May, L.A., Butt, C., Minor, L., Kolbinson, K. and Tulloch, K. (2003). Measurement Reliability of Functional Tasks for Persons Who Self-Propel a Manual Wheelchair. *Archives of Physical Medicine and Rehabilitation*, 84: 578-583.

## **APPENDIX H: MANUAL MUSCLE TESTING (MMT)**

### **AIM**

A standardized assessment to measure muscle strength

### **EQUIPMENT**

- None

### **PROCEDURE**

Resistive tests are performed on select muscles in the arms and trunk. These MMT are performed in the individual's wheelchair. Muscle testing is an important component of the physical assessment. Muscles are graded on a five-point ordinal scale used in manual muscle testing with evidence to support well-established validity and reliability of this testing (Hislop and Montgomery, 2007).

#### **The following muscles was tested:**

1. Wrist flexors and extensors
2. Deltoids – shoulder abductors
3. Triceps – elbow extension
4. Biceps – elbow flexion
5. Internal and external rotators – internal and external rotation with a bent elbow

### **SCORING**

The five-point scale is defined as:

0 - Complete lack of voluntary muscle contraction. The examiner is unable to feel or see any muscle contraction.

1 - Faint or “flicker” muscle contraction without any movement of the limb. The examiner can see or palpate some contractile activity of the muscle/s or may be able to see or feel the tendon “pop up” or tense as the athlete tries to perform the movement.

2 - Very weak muscle contraction with movement through complete range of motion in a position that eliminates or minimizes the force of gravity. This position is often described as the horizontal plane of motion.

3 - Muscle can complete a full range of motion against only the resistance of gravity.

4 - Able to complete the full range of motion against gravity and can tolerate strong resistance without breaking the test position. The Grade 4 muscle clearly breaks with maximal resistance.

5 - Able to complete full range of motion and maintain end point range position against maximal resistance. The examiner cannot break the athlete's hold position.

### **VALIDITY**

Not established



## **RELIABILITY**

Excellent interrater reliability (ICC=0.94)

## **REFERENCE**

Criteria are defined according to Hislop HJ, Montgomery J. Daniels and Worthingham's *Muscle Testing: Techniques of Manual Examination. 8th ed.* Philadelphia, Penn: WB Saunders, 2007.

## **APPENDIX I: REINTEGRATION TO NORMAL LIVING INDEX (RNLI)**

### **AIM**

To measure participation and assesses quantitatively the degree to which individuals who have experienced traumatic or incapacitating illness achieve reintegration into normal social activities.

### **EQUIPMENT**

None

### **PROCEDURE**

11 declarative statements and focused on seven domains.

- The 7 domains include:
  - Indoor
  - Community and distance mobility
  - Self-care
  - Daily activities (work and school)
  - Recreational and social activities
  - Family role(s)
  - Personal relationships
  - Presentation of self to others and general coping skills
- First 8 items represent 'daily functioning' and the remaining 3 items represent 'perception of self.'
- Each domain is accompanied by a visual analogue scale (VAS, 0 to 10 cm); the VAS is anchored by the statements:
  - "Does not describe my situation" (1 or minimal integration)
  - "Fully describes my situation" (10 or complete integration)

### **SCORING**

- Adjusted score =  $(\text{Total score}/110) \times 100$ 
  - Total score = sum of all 11 items
  - Minimum score = 0
  - Maximum score = 100

### **VALIDITY**

The 3-factor model was an appropriate fit (RMSEA 0.067, CFI0.963; TLI0.986). It also has good concurrent and construct validity.

### **RELIABILITY**

Internal consistency  $r=0.9$ .

When patients and significant other fill in the forms  $r = 0.62$  when compared to when health care professionals and the patient fill in the form  $r = 0.39$ .

**REFERENCE**

Wood-Dauphinee S.L., Opzomer, M.A., Williams, J.I., Marchand. B., Spitzer, W.O. (1988). Assessment of global function: The Reintegration to Normal Living Index. *Archives of Physical Medicine and Rehabilitation*, 69:583-590.

**Modified Reintegration to Normal Living Index (mRNL Index)**

For each of the following statements, please indicate how well each statement describes you and/or your situation by placing a mark in a box. Please mark only one box per question.

	Does not describe me or my situation	Sometimes describes me or my situation	Mostly describes me or my situation	Fully describes me or my situation
1. I move around my house as I need to.				
2. I move around my community as I need to.				
3. I am able to make longer trips as I need to.				
4. I am comfortable with how my self-care needs are met (dressing, feeding, toileting, bathing).				
5. I spend most of my days occupied in work activity that is necessary or important to me (such as paid or voluntary work, housework, or studying etc.).				
6. I am able to participate in recreational activities as I want to (hobbies, crafts, sports, reading, television, games, computers etc.).				
7. I socialise with friends, family and/or business acquaintances as I want to or is necessary.				
8. I have a role in my family which meets my needs and those of my family members. (Family means people with whom you live and/or relatives with whom you don't live but see on a regular basis.)				
9. In general, I am comfortable with my personal relationships.				
10. In general, I am comfortable with myself when I am in the company of others.				
11. I feel that I can deal with life events as they happen.				

Miller, A. Clemons, L. & Luzzin, N. Measurement properties of a modified Reintegration to Normal Living Index (mRNL Index) in an adult rehabilitation population. Manuscript submitted for publication  
 Wood-Dauphinee S, Opzomer A, Williams J, Marchand B, Spitzer W. Assessment of global function: The Reintegration to Normal Living Index. *Arch Phys Med Rehabil* 1988;69:583-90

## **APPENDIX J: TRAINING PROGRAM OUTLINE FOR THE VOLUNTEERS**

Below is the outline of the training manual that was designed to train volunteers in a community based setting. Following the outline is the slide show that was used to conduct the theoretical part of the training.

1. What is a SCI and how to identify any problems in terms of secondary health conditions
2. How to work with persons with a SCI
3. What is physical activity
  - a. Basic information about physical activity
  - b. How to use RPE scale
4. How to use adapted equipment/how to adapt equipment to the needs of the patient
5. How to follow the emergency procedures in the event of an injury

**Spinal Cord Injury**  
**Community Based Physical Activity Training**

Candace Vermaak  
 January 2015

**Chapter 1: Introduction to Spinal Cord**

- What is the Spinal Cord?
- What is a Spinal Cord Injury?
- How is an injury classified?
  - Paraplegic
  - Tetraplegic
  - Complete injury vs Incomplete injury

**Chapter 1: Introduction to Spinal Cord**

**C4 injury**  
 Quadriplegic  
 Tetraplegic, results in complete paralysis below the neck

**C8 injury**  
 Results in partial paralysis of hands and arms as well as lower body

**T8 injury**  
 Paraplegia, results in paralysis below the chest

**L1 injury**  
 Paraplegia, results in paralysis below the waist

• Figure 1: Spinal Cord ([www.spinalinjuries.ie](http://www.spinalinjuries.ie))

**Chapter 2: Basic Anatomy**

**Chapter 2: Anatomy**

Segment	Key muscles	Movement	Function
C1-3	-	-	Dependent on ventilation
C4	-	-	Electrical wheelchair
C5	Biceps brachii	Elbow flexion	Manual/electrical wheelchair
C6	Ext. carpi rad. long.	Wrist extension	Manual wheelchair, easy transfers, personal hygiene
C7	Triceps brachii	Elbow extension	Manual wheelchair, ADL
C8	Flex. Dig. Long	Finger flexion	Manual wheelchair, ADL, car
T1	Abd. dig. V	Spreading fingers (digV)	
T2-T6	-	-	Limited standing and locomotion orthoses + walker
T6-T12	-	-	
L2	Iliopsoas	Hip flexion	Gait with orthoses, frame
L3	Quadriceps	Knee extension	Gait with orthoses, crutches, stick
L4	Tib. ant.	Ankle dorsiflexion	
L5	Ext. hallucis long.	Big toe extension	
S1	Triceps surae	Ankle plantar flexion	Normal gait

**Chapter 3: Common Complications & Secondary Conditions**

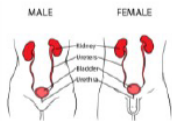
- Pressure Sores
- Symptoms and treatment:
  - The pressure sore will result in the person sweating excessively, having headaches and just be without any energy
  - Seek medical attention
  - No physical training is allowed until the pressure sore is healed

### Chapter 3: Common Complications & Secondary Conditions

- Urinary Tract Infections

**Symptoms and treatment:**

- Bladder infections are potentially lethal for persons with a SCI and the person should not exercise if they have one.
- If the person is unaware that they have one, the person might have a fever, has chills or if there is blood in his urine they should call their doctor.
- Remember, if the urine in the leg bag is cloudy, brown, red or smells, it could be a sign of infection.



**Symptoms and treatment:**

- The UTI will result in the person sweating excessively, having headaches and just be without any energy.
- Nausea and vomiting may also be a sign of an infection.
- Pain in the lower belly.
- Pain on one side of the back (behind the ribs).
- Pain or a burning sensation when urinating.
- Seek medical attention

### Chapter 3: Common Complications & Secondary Conditions

- Autonomic Dysreflexia
- Symptoms and treatment:
  - Sweating on face, arms, or chest ( usually above his level of injury)
  - Bad headache caused by increased blood pressure
  - Red, blotchy skin on face, arms, or chest above his level of injury
  - Pale skin below the level of injury
  - Raised blood pressure
  - Stuffy nose and trouble breathing
  - Blurring of vision or spots before his eyes
  - "Goosebumps" on arms, chest
  - Slow pulse
  - AD is dangerous and if it occurs, it should be treated as a medical emergency and it may require a doctor's care
  - No training

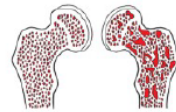
### Chapter 3: Common Complications & Secondary Conditions

- Pneumonia
- Symptoms and treatment:
  - Has a fever, shortness of breath, has trouble coughing up secretions (mucus) to clear his lungs, or the secretions are not clear or white, this could be a sign of lung infection.
  - Fatigue and muscle aches
  - Headache
  - Diseases of the respiratory system are also a major cause of death in persons with a SCI.
  - Seek medical attention
  - No training



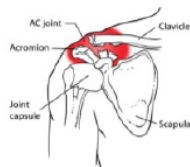
### Chapter 3: Common Complications & Secondary Conditions

- Musculoskeletal Issues:
  - Osteoporosis
  - Symptoms and treatment:
    - No symptoms in the early stages of osteoporosis
    - Fractures
    - Treatments include:
      - Lifestyle changes, such as diet and exercise
      - Taking calcium and vitamin D
      - Using medicines



### Chapter 3: Common Complications & Secondary Conditions

- Musculoskeletal Issues:
  - Shoulder overuse
  - Symptoms and treatment:
    - Chronic pain in the shoulder area
    - Muscle weakness in the affected area
    - No training



### Chapter 3: Common Complications & Secondary Conditions

- Musculoskeletal Issues:
  - Muscle contractures
  - Symptoms and treatment:
    - Physical therapy and surgery
    - Stretching
    - Splinting
    - Electrical stimulation



### Chapter 4: How to apply Physical Activity (PA) in the SCI Population

- What is PA?
- Health related fitness components:
  - Cardiovascular endurance

Duration	Frequency	Intensity	Test
20-60min/session	3-5 days per week	RPE= 3-6	12min wheel

RPE will be used as a guide to determine the fatigue (tiredness) of the participants during PA

### Chapter 4: How to apply Physical Activity (PA) in the SCI Population

- Health related fitness components:
  - Strength training

Duration	Frequency	Intensity	Test
2-3 sets of 8-12 repetitions	2-4 days per week	RPE= 3-6	One stroke push

### Chapter 4: How to apply Physical Activity (PA) in the SCI Population

- Health related fitness components:
  - Flexibility

Duration	Frequency	Intensity	Test
Before aerobic/strength exercises	3-5 days per week	/	Forward vertical reach

### Chapter 4: How to apply Physical Activity (PA) in the SCI Population

- Health related fitness components:
  - Functional exercise

Duration	Frequency	Intensity	Test
10-15min per session	2 days per week	RPE= 3-6	One stroke push Forward vertical reach

Problems with exercise in SCI	Precautions for exercise	Benefits of exercise in SCI
Impaired thermoregulation	Fluid intake	Bone Decreased rate of bone density loss but inconsistent findings on improving bone density Increased strength and endurance of the muscles
Reduced heat loss via evaporation (decreased sweating below the lesion) using the upper limbs only	Clothing: wet and not too tight	Cardiovascular Efficiency of the cardiovascular system (increase of the stroke volume, decrease of the heart rate) Decrease of the total peripheral resistance in the blood vessels (increased muscle mass & vasodilatation) Reduced blood pressure (BP) during exercise
More thermal stress	Very low intensity exercise starting level	
Risk of heat stroke/exhaustion >38-40°	Small increments	
Risk of autonomic dysreflexia (also due to FES)	Ensure cooling down: fluids, shadow, move calmly	
Blood pooling	Can lead to fainting/dizziness	Helps to ensure that adequate circulation reaches skeletal muscles, heart and brain

### Chapter 4: How to apply Physical Activity (PA) in the SCI Population

- How to monitor exercise session
  - Rate of Perceived Exertion (RPE)

### Chapter 5: Practical Aspects in Working with SCI patients

- Screening questions
- How to use/adapt equipment within the SCI population
  - How to attach hand straps
    - See practical part of the training
  - How to do transfers
    - See practical part of the training
- Special considerations
  - Depression is common amongst people with a SCI, so be supportive
  - Always supervise someone with tetraplegia/quadruplegia
  - Make sure participants stay hydrated during the sessions especially on hot summer days
  - Always treat people with a disability as you would any other person

### Chapter 6: Physical Activity Program

Type of Activity	Exercise	Intensity	Duration (Will vary with each week)
Warm up	Arm ergometry	RPE = <6	10-20min
Aerobic/Cardiovascular	Wheelchair pushing		
Strength	Biceps (Elbow flexion) Triceps (Elbow extension) Deltoids (Shoulder lifters) Latissimus Dorsi (Shoulder extension and adductor) Rhomboids (Scapula and shoulder stabiliser)	RPE = <6	2 x 10 reps 15-20min
Functional	Balance Chair lifting Weight shifting Finding centre of gravity	RPE = <6	10-15min
Flexibility	Stretching the muscles of the anterior shoulder	RPE = <6	10min

### Chapter 6: Physical Activity Program

Type of Activity	Exercise	Check points
Warm up	Arm ergometry	Right distance from the handles to give maximum range of motion
Aerobic/Cardiovascular	Wheelchair pushing	Fulcrum of handles should be at shoulder level Make sure the person is seated correctly and stable and in the middle of the machine Ensure that there are no slippery surfaces or obstacles that could result in injury
Strength	Biceps (Elbow flexion) Triceps (Elbow extension) Deltoids (Shoulder lifters) Latissimus Dorsi (Shoulder extension and adductor) Rhomboids (Scapula and shoulder stabiliser)	Sit up straight Keep the head straight Relax the shoulders and pull them slightly backwards and down (bunny jumps over the hill) Breathe in when the muscle is relaxed and breathe out when the muscle is moved (contracted) For quadriplegics make sure the hand straps are fitted correctly and that the thumb is not strapped in. Make sure the straps are tight so to avoid weights falling out
Functional	Balance Chair lifting Weight shifting Finding centre of gravity	Make sure the area is safe Assist participant where needed
Flexibility	Stretching the muscles of the anterior shoulder (biceps, anterior deltoid, pectoralis)	Do not overstretch Only a light stretch should be felt



## APPENDIX K: BASIC SCREENING QUESTIONS AND PHYSICAL ACTIVITY PROGRAM

The details of the PA program is summarized in table 3.

**Table 3: Physical activity program**

Activity	Duration / Set	Repetition	Detail
Screening questions	5 min		Do you have open wounds/pressure sores/bladder infection/any other infection? Do you have fever? Do you have any of these symptoms? Headache Dark/strong smelling urine Abdominal pains Increased spasms. Check above lesion sweat level Do you have any shoulder pain?
Cardiovascular Exercise	10-20min		Arm Ergometry / Rolling
Resistance Exercises	15 -20min	2 x 10	Biceps Triceps Deltoids Latissimus Dorsi Rhomboids
Functional Exercises	10-15min		Balance Chair Lifting Weight Shift Finding Centre of Gravity
Flexibility Exercises Stretching	5min /		Anterior Shoulder

**PERIODIZATION**

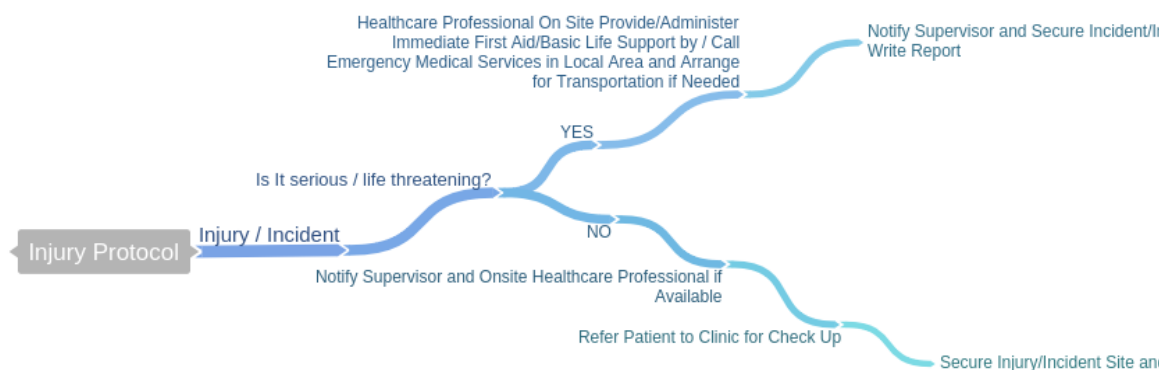
Each week the intensity of the program will be increased either by the number of sets, the number of repetitions or by increasing the weight used.

**Table 4: Periodization of the physical activity program**

<b>Week</b>	<b>Set</b>	<b>Repetition</b>	<b>Weight</b>
1 and 2	2	10	Dependent on patient
3	3	10	
4	3	12	
5	2	10	
6	3	10	Increase weight by 500g-1000g
7	3	15	
8	3	15	Increase weight by 500g-1000g

## APPENDIX L: INJURY PROTOCOL

If any injury is sustained during the testing or physical activity sessions the following protocol will be followed:



**Figure 1: Injury Protocol**

### CRITICAL INJURY

An injury of a serious nature that,

- a. Places life in jeopardy,
- b. Produces unconsciousness
- c. Results in substantial loss of blood;
- d. Involves a fracture of a leg or arm, but not a toe or finger
- e. Involves an amputation of a leg, arm, hand, or foot, but not a finger or toe.
- f. Consists of burns to a major portion of the body; or
- g. Causes the loss of sight in an eye.

### SUPERVISOR CONTACT DETAILS

Candace Vermaak  
Cell: 082 782 1625

### MEDICAL/EMERGENCY SERVICES

**WCRC:** Lisa Fincham  
Tel: Extension 2414

**Strand:** Candace Vermaak /  
Clinic  
Tel: 082 782 1625 / 021 853  
3380

**Macassar:** Candace  
Vermaak / Clinic  
Tel: 082 782 1625 / 021 857  
2330

## APPENDIX M: ACCEPTANCE LETTERS FROM SENECIO AND WESTERN CAPE REHABILITATION CENTRE



**WESTERN CAPE REHABILITATION CENTRE**  
for Persons with Physical Disabilities



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REFERENCE: PhD  
ENQUIRIES: Ms J A Hendry

### TO WHOM IT MAY CONCERN

#### PHD IN SPORT SCIENCE: CANDACE KOK (VERMAAK)

Mrs C Vermaak has been given provisional acceptance by the Western Cape Rehabilitation Centre (WCRC) to conduct the practical aspect of her PhD Research Thesis [entitled "Bridging the gap from inpatient rehabilitation to sustainable health and wellness in spinal cord injured individuals"].

Once ethical approval has been granted by the University of Stellenbosch, she is required to submit her protocol, together with the required Annexure, to the Department of Health Research Committee for final approval.

Please contact me should you have any further queries.

Yours Sincerely,

A handwritten signature in black ink, appearing to read "Jenny Hendry".

**MS JENNY HENDRY**  
CEO: WCRC  
DATE: 03-03-2014

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[www.wcrc.go.v.za](http://www.wcrc.go.v.za)  
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W: [www.senecio.org.za](http://www.senecio.org.za)

NPC Reg No: 2008/026954/08

Public Benefit Organisation No: 930034732

Directors: A van Niekerk, F Marais, T Alfred

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10 March 2014

Dear Candace Vermaak

***PhD Research: Bridging the gap from inpatient rehabilitation to sustainable health and wellness in individuals with spinal cord injuries.***

Senecio gives written consent to Candace Vermaak to work with the beneficiaries that Senecio supports in the community. We understand that the individuals will be required to complete questionnaires, and take part in the study at the facilities that we currently use should they meet the criteria.

Kind Regards

Elizabeth Ward

**SCI Programme Manager**

Email: [liz@senecio.org.za](mailto:liz@senecio.org.za)

Tel: 021 852 3856

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