PHYSICAL ACTIVITY BEHAVIOUR OF COMMUNITY DWELLING PERSONS WITH TRAUMATIC SPINAL CORD INJURIES IN CAPE TOWN, SOUTH AFRICA

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KEYWORDS

Traumatic spinal cord injury

Persons with traumatic spinal cord injury

Physical activity

Sedentary physical activity

Light-intensity physical activity

Moderate physical activity

Vigorous physical activity

Secondary complications

Functional independence

Cape Town

South Africa

KEY TERMS

Community-dwelling participants- people who sustained a TSCI and live within their community

Community participation- the perception of how an individual is able to participate within their community that they once lived in prior to their injury (Hammel, 2007).

Complete injury

AIS A- No motor or sensory function is preserved in the sacral segments S4-S5 (Roberts, Leonard & Cepela, 2017).

Incomplete injury

AIS B- Sensory function, but no motor function, is preserved below the neurologic level, which includes the sacral segments S4-S5 (Roberts, Leonard & Cepela, 2017).

AIS C- Motor function is preserved below the neurologic level, and more than half of the muscles below the neurologic level have a muscle power grade less than 3 (Roberts, Leonard & Cepela, 2017).

AIS D- Motor function is preserved below the neurologic level, and at least half of the muscles below the neurologic level have a muscle power grade of 3 or more (Roberts, Leonard & Cepela, 2017).

AIS E- motor and sensory function are normal and intact (Roberts, Leonard & Cepela, 2017).

Mortality- total number of deaths within a period of time (Rothman, 2012).

Participation- includes the involvement in daily life events according to the ICF (Dijkers, 2005; WHO, 2002).

Physical activity- refers to any movement produced by the bodies skeletal muscles that require energy expenditure (Martin Ginis et al., 2018).

Physical activity behaviour- is quantified as volume and/or intensity. Intensities are often developed based on energy expenditure (Holmlund, Ekblom-Bak, Franzén, Hultling & Wahman, 2019).

Secondary complication- an impairment, injury or disability, which occurs as a result of a primary condition (Krause, Reed & McArdle, 2010).

ABBREVIATIONS

ADLs	Activities of Daily Living
CVD	Cardiovascular disease
DM	Diabetes mellitus
EE	Energy expenditure
ICF	International classification of functioning, disability and health
LOS	Loss of sensation
LTPA	Leisure time physical activity
MET	Metabolic equivalent
MVA	Motor vehicle accident
PA	Physical Activity
PwSCI	Persons with Spinal Cord Injury
QoL	Quality of Life
SCI	Spinal Cord Injury
SCIM-SR	Spinal Cord Injury Measure- Self report
SED/LIPA	Sedentary and light physical activity
TSCI	Traumatic Spinal Cord Injury
UTI	Urinary tract infection
VMC	Vector magnitude counts
WHO	World Health Organisation

ABSTRACT

Background: A spinal cord injury is a devastating condition, associated with permanent disability and decreased life expectancy. Persons with spinal cord injuries (PwSCIs) often lead sedentary lifestyles, which set in motion a cascade of comorbidities linked to lifestyle behaviours. There is growing evidence indicating that decreasing sedentary behaviour and improving physical activity (PA) are connected to favourable rehabilitation outcomes namely health status and physical functioning. There is paucity of evidence to support this postulation in our setting.

Aim: The aim of this study was to assess PA behaviour of traumatic spinal cord injury (TSCI) patients in Cape Town/Western Cape.

Methods: A quantitative cross sectional design was employed in this study. The population consisted of community- dwelling adults with traumatic spinal cord injuries (TSCIs). Only individuals who have lived in the community for at least one year following injury were recruited. Participants were sourced from the database (2016-2020) of Groote Schuur Hospital, Cape Town using a sample of convenience. A total of 403 adults with spinal cord injuries (SCIs) was retrieved from the database (2016-2020). From the 297 people who met the inclusion criteria, 76 participants were included in the study. A large proportion (n=214) could not be reached, 10 relocated to other areas and provinces in South Africa, and 2 declined to participate in the study. The study took place in 42 communities of the Cape Metropole. Questionnaires capturing the epidemiologic profile, current secondary medical complications, and functional status were administered. PA behaviour was measured objectively by means of an Actigraph wGT3X-BT accelerometer. The data was transferred into an Excel spreadsheet for coding purposes before being imported to SPSS v.28 for analysis. Descriptive statistics were used to summarise the data. Furthermore, the student T test was used to determine the association between physical activity and exposure variables each of gender, age, time since injury and mobility status. The accelerometer data was downloaded using the Actilife 6 software and subsequently analysed using 60secs epochs.

Results: The mean age of the participants (n=76) was 36 years with 88% being male. Sixty-five per cent of participants had TSCIs due to assault. Concerning secondary complications, 86% of participants reported three or more complications with the most common complication reported as muscle spasms (87%), followed by joint and muscle pain (72%). A significant association was seen between mobility status, where wheelchair users presented with a greater

prevalence of "injuries due to loss of sensation" (Chi square 8.128: p= 0.006) than walkers. With regard to functional status, participants reported the most independence with tasks involving the use of the upper limb. A significant association was found in mobility status (wheelchair users vs. walkers) for the self-care subscale (t= -2.689; p <0.001), respiratory and sphincter management subscale (t= -5.631; p= 0.022), and overall total scores (-7.120; p <001). With objectively-assessed PA, participants spent the majority of their time engaged in sedentary and light physical activity (SED/ LIPA), at 98.3% reported for wheelchair users and 99.8% for walkers. Less time was spent in moderate and vigorous PA. With respect to the stratified analyses, significant associations were found for exposures related to PA behaviour: those between 3-6 years since injury (t= -1.514: p= 0.019) spent significantly more time in vigorous PA than those living with the injury between 1-2 years; wheelchair users spent more time in moderate PA (t= 1.659: p=0.012) and vigorous PA (t= 1.681: p= 0.008) than walkers; and those 45+ age group (t= -2.543: p <0.001) spent significantly more time in moderate PA than their younger counterparts (18-44 year).

Conclusion: Overall, this study found that PwSCIs experience a range of secondary medical conditions and functional limitations were still prominent. Furthermore, PwSCIs regardless of mobility status, age, gender or duration of injury, spent most of their time in sedentary or light activity level. We further found that wheelchair users were more physically active than walkers. Additionally, older wheelchair users were more engaged in moderate PA compared to younger participants, and those living with their injuries for a longer time were more engaged in vigorous PA compared to those with recent injuries. This study highlights the need for PA promotion interventions as well as provides insights into the subgroups that are more prone to physical inactivity and suboptimal levels of performance. An immediate need exists to understand the rehabilitation needs of walkers as well as determine the expertise of rehabilitation professionals in treating walkers with SCI to enable community ambulation and improved fitness.

DECLARATION

I declare that *Physical Activity Behaviour of Community-Dwelling Persons with Traumatic Spinal Cord Injuries in Cape Town, South Africa,* is my own work, that it has not been submitted for any degree, or examination in any other university, and that all the resources I have used or quoted have been indicated, and acknowledged by complete references.

Full name: Aeysha Gabriels Date: November 2023

Signed: 

DEDICATION

This thesis is dedicated to my father Mogammad Makkie Smith Al-Marhoom for his unconditional and unwavering love, support and sacrifices. A father, whose primary concern until his last moments, was his family. My father, you were my best friend and biggest supporter. I will always strive to make you proud. Thank you for supporting my dreams and helping me achieve them. May your resting place always be peaceful and beautiful. May the light never dim in your grave, may your grave be among the gardens of *Jannah* and may you be granted *Jannah* without reckoning. *Insha-Allah*

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CHAPTER ONE

INTRODUCTION

1.1. Introduction

This chapter provides background information on spinal cord injuries, specifically definitions and epidemiology of traumatic spinal cord injuries. The effects of spinal cord injuries on a person's functioning, secondary complications and physical activity are also discussed. Additionally, the chapter discusses the impact of physical activity of community- dwelling persons with traumatic spinal cord injury.

1.2. Background

In the year 2013, the World Health Organisation (WHO) reported that there are between 250 000 and 500 000 people who sustain a spinal cord injury (SCI) each year (World Health Organization, 2013). SCIs are either classified as traumatic or non-traumatic in nature (causation). Traumatic spinal cord injuries (TSCIs) are often a result of preventable causes such as falls, motor vehicle accidents (MVA), violence /assault or sport-related injuries, whereas non-traumatic conditions occur as a result of underlying pathologies (Draulans, Kiekens, Roels, & Peers, 2011; Hart and Williams, 1994; World Health Organization, 2013;). Joseph et al. (2015) report that assault i.e., gunshots, stab wounds and use of non-penetrating objects were the leading causes of TSCIs, accounting for 60% of casualties in the Cape Metropole. SCIs are highly problematic and the occurrence will almost never be eradicated but it leads to longstanding disability (Joseph et al., 2013; Nash, 2005; Rahimi- Movaghar et al., 2013). A SCI renders a person paralysed, which makes the maintenance of normal physical behaviour difficult. Physical activity (PA) is an important target for PwSCIs; not only for prevention of secondary conditions, activity and participation restrictions but also for disease prevention, primarily for cardiovascular disease (CVD) (Kehn and Kroll, 2009; Nooijen et al., 2015; Sisto and Evans, 2014).

Disability is common after a SCI. This occurs due to damage of the spinal cord, which results in impairments of motor and sensory function, which often leads to temporary and permanent

disability (Nash, 2005). SCIs are further classified by The American Spinal Injury Association (ASIA) Impairment Scale (AIS), which is a five-graded scale used to identify the severity of the injury sustained. AIS A is classified as complete injuries and AIS B/C/D are classified as incomplete injuries (Roberts, Leonard & Cepela, 2017). PwSCIs often have permanent neurological disability, which predisposes them to early deaths (Hitzig, Eng, Miller & Sakakibara, 2011). The impact of a SCI can be described using the International classification of functioning, disability and health (ICF). Two central concepts in the ICF relate to human functioning and disability. Human functioning is defined as functioning at the level of the body or body chart, and the whole person in a social context, whereas disability from this biopsychosocial lens refers to the dysfunction at one or more of the same levels, namely impairments, activity limitations and participation restrictions (WHO, 2002). It also considers how environmental and personal factors influence the impact of disability. The ICF core sets define SCI related problems with functioning into impairments of the autonomic nervous system which, in turn, impact activities of daily living (ADLs), general mobility and PA (WHO, 2002).

A SCI is a common condition that leads to long-term disability and currently a public health concern (Warms, Whitney & Belza, 2008). According to Joseph et al. (2015), the incidence rate of TSCIs, in South Africa, is 76 per million which was shown to be of the highest in the world as opposed to developed western countries. Developed countries have specialised systems in place, such as advanced specialised acute care and acute transportation, resulting in increased survival rates, decreased first-year mortality rates and improved neurological recovery (Furlan, Noonan, Cadotte & Fehlings, 2011; WHO, 2013).

Furthermore, a modifiable factor found to decrease the risk of impairments (secondary complications) is PA (Wolfe et al., 2013). It is well known that lack of activity has devastating consequences on health status. Prolonged bedrest can lead to physiological detriments such as muscle deconditioning and atrophy, slower metabolism, loss of bone density, decreased control with blood pressure and an increased risk of developing heart disease, diabetes and obesity (Warms, Whitney & Belza, 2008). Engaging in PA has proven to positively affect the general wellbeing of PwSCIs and reduce the risks involved with secondary complications post injury (Nooijen et al., 2015; Sisto and Evans, 2014). Various factors have been associated with

functional recovery and social interaction of PwSCIs. Impairments such as pain, loss of motor and sensory control and UTIs has been shown to negatively impact personal function, as well as PA and participation (Kennedy, Lude, Elfström & Smithson, 2010; Müller, Peter, Cieza & Geyh, 2012). The WHO recommends that able-bodied individuals should perform approximately 150-300 min/week of moderate to vigorous intensity exercise or at least 75mins of vigorous exercises, which include a muscle-strengthening programme twice a week. This is the recommended exercise regime to decrease morbidity and mortality rates among able-bodied individuals (Martin Ginis et al., 2018). The recommended PA for SCIs which has cardio metabolic and health fitness benefits, is approximately 30 minutes of moderate to vigorous exercise three times a week (Martin Ginis et al., 2018). PA has shown to play an important role in SCIs as it reduces the risk of developing secondary complications. The long-term benefits include improved cardiovascular fitness and muscle strength; improved fatigue; decreased depression; improved family and social interaction and reduced disease-associated pain (Wu and Williams, 2001). It has shown to improve participation, which could, in turn, improve community reintegration. Despite all the health benefits of PA, PwSCIs continue to be the most inactive and studies report an alarming increase in sedentary lifestyle, increased risk of developing secondary complications and minimal participation in PA as well as the onset of CVD (Calder et al., 2018; Kehn and Kroll, 2009).

Previous literature described PA of adults with disabilities by means of self-report measures such as surveys, questionnaires or observation. Surveys generally report low levels of PA, poor participation in leisure time physical activity (LTPA) and sport and recreational activities. This approach was cost-effective, convenient, easy to administer and prevented behaviour objection (Warms, Whitney & Belza, 2008). Despite the convenience of these subjective measurement tools, it does not allow adequate representation of PA and it is unable to effectively report on PA as an objective marker of health and wellbeing. A valid means of measuring PA in individuals is to measure the level of energy expenditure (EE) by means of assessing activity type, and intensity, frequency and duration of activity. Objective measurement tools have in recent years provided a more accurate representation of EE providing volume and intensity of activities. The use of activity monitors such as accelerometers has shown to be more sensitive at detecting activity levels and the ability to quantify the PA by means of cut-points. Furthermore, cut-points are derived and differ according to placement and activity, with wheelchair users' intensity best monitored on the wrist and walkers best monitored on the ankle

for determining intensity levels (Bammann, Thomson, Albrecht, Buchan & Easton, 2021; Warms, Whitney & Belza, 2008). Previous studies have demonstrated that both moderate and vigorous PA can lead to improved physiological health fitness and improved quality of life (QoL) in sedentary individuals (Bammann et al., 2021).

According to a study conducted by Kehn and Kroll (2009), PA improves functional abilities, QoL, and social integration of individuals living with a SCI. Living a physically active lifestyle improves both objective and subjective QoL, in PwSCIs (Tomasone, Wesch, Martin Ginis & Noreau, 2013; Warburton, Nicol & Bredin, 2006). These individuals have also further reported that participation in work and community activities directly influences their perception of QoL. Individuals with SCI often face challenges returning to their previous social and community roles, due to changes in their mobility status after an SCI. Fatigue with mobility set in due to decreased endurance and difficulty keeping up with a physically demanding environment (outdoor terrain) encountered in the community. This can lead to withdrawal from society, decreased activity and QoL (Van der Westhuizen, Mothabeng & Nkwenika, 2017).

PwSCIs are faced with major life changes in their living circumstances, personal relationships and lifestyle adaptations. Reintegration into their normal life roles and establishing a valuable family role becomes priority (Hammell, 2007). Rehabilitation plays an important role in educating and teaching people, who sustained a SCI, the necessary skills to adjust to life after the injury (Forchheimer and Tate, 2004; Groah et al., 2012). A major component of this rehabilitation is PA, and the absence thereof has shown to be correlated with morbidity and mortality.

1.3. Problem Statement

PwSCIs have an increased risk of developing serious health complications. Factors such as secondary health conditions, poor eating habits, low educational status and household income contributes to sedentary lifestyle. Promotion of PA plays an important role in the prevention of these secondary complications and mortality. Research has shown the positive impact and benefits PA has on both able-bodied individuals and those with disabilities (Thietje, Pow, Schulz, Keenest, & Hirschfeld, 2011). Despite the known benefits of PA for SCIs, most

individuals lead inactive and sedentary lifestyles. This predisposes them to CVD, which is the leading cause of mortality in developed countries (Thietje et al., 2011). Leading a physically active lifestyle has also shown to improve QoL, but limitations in community and environment such as physical structures, assistance, policies or attitudes have negatively impacted this perception, overall health and participation in society. Despite the extensive global research on PA, little is known about PA within the SCI community in South Africa's Cape Metropolitan region. This is of interest as the sociodemographic profile of TSCI is unique in South Africa, where mostly young males between the ages of 16 and 30 are affected. This group, arguably, has a longer life to live with the SCI and therefore may be reliant on the healthcare system for a longer period of time, which may influence life-time healthcare utilisation and societal costs. It is therefore important to explore the potential role of PA behaviour in SCI rehabilitation. Hence our study aimed to assess physical activity behaviour of TSCI patients in Cape Town/Western Cape.

1.4. Study Aim

The aim of this study was to assess physical activity behaviour of TSCI patients in Cape Town/Western Cape.

1.5. Research Questions

1.5.1. What is the socio-demographic profile and injury characteristics of community- dwelling adults with TSCIs in South Africa?

1.5.2. What are the secondary complications and functional independent indices of community-dwelling adults with TSCIs in South Africa?

1.5.3. What is the PA behaviour, i.e., time spent in different intensities, of community-dwelling adults with TSCIs in South Africa?

1.5.4. Are there any differences in time spent in different PA intensities between different known sub groups (gender, years living with SCI, age) of persons with TSCIs?

1.6. Study objectives

1.6.1. To determine the socio-demographic profile and injury characteristics of community-dwelling adults with TSCIs, in South Africa.

1.6.2. To determine secondary complications and functional independent indices of community- dwelling adults with TSCIs in South Africa.

1.6.3. To determine PA behaviour, i.e., time spent in different intensities, of community-dwelling adults with TSCIs in South Africa.

1.6.4. To determine any differences in time spent in different PA intensities between different known sub groups (gender, years living with SCI, age) of persons with TSCIs.

1.7. Significance of study

This study provides the objective measurement of PA behaviour with regard to volume and intensity within community- dwelling adults with TSCIs. PA is compromised after a SCI and this could lead to increased weight gain, and an increased risk of CVD, which has become a leading cause of death in developed countries. Having co-morbidities coupled with poor fitness limit function, community and social participation. This study will provide valuable information regarding the role of PA in SCI rehabilitation. This could be used to influence improvements in healthcare services aligned with PA to inform rehabilitation plan before and after discharge. This research would provide valuable initial data to assist with the design, development and implementation of contextually relevant interventions to promote PA.

1.8. Outline of the thesis

Chapter One provides the background to the study. An overview and importance of physical activity for community- dwelling participants, with traumatic spinal cord injuries, is outlined. The significance, aims and objectives of the study are also presented. This chapter concludes by providing the structure of the thesis.

Chapter Two presents the literature that is relevant to the study, and provides an overview of SCIs, secondary complications, functional independence and objectively-assessed physical activity measurement. In addition, the study's theoretical framework is discussed.

Chapter Three provides the methodological issues pertaining to the study. The research setting, study design, population and sampling are also presented. Furthermore, instrumentation tools to collect data are discussed in detail, including data collection procedure, and reliability and validity of the tools defined. The chapter concludes with data analysis and ethical considerations and issues that were addressed during the research.

Chapter Four discusses the data and findings by means of tables and graphs.

Chapter Five explores and discusses the findings in relation to the relevant literature, and comparisons and differences are highlighted. The results of the study are then linked to the ICF, which is the theoretical framework of the study.

Chapter Six provides a summary on the main aspects of the study. Limitations of the study and recommendations for future research area also discussed.

CHAPTER TWO

LITERATURE REVIEW

2.1. Introduction

This chapter provides an overview of spinal cord injuries, including literature on the prevalence and incidence of spinal cord injuries. In addition, literature on secondary complications, functional independence and physical activity is reviewed. An overview of the ICF is provided as a conceptual framework of the study.

2.2. Overview of Spinal Cord Injury

The WHO (2013) describes a SCI as a complex medical and life disrupting condition. It often results in permanent disability and significant life changes for the patient and their families (Mehdar, Mahjri, Al Rashah & Alyazidi, 2019). Depending on the level and severity of the injury, patients are either classified as quadriplegic or paraplegic (Alizadeh, Dyck & Karimi-Abdolrezaee, 2019). In a local study done by Joseph et al. (2015), it was established that injury to the cervical region (c1-8) was the most common, accounting for 53.1% of TSCIs, followed by the thoracic region accounting for 38.6%. Damage to the lumbar and sacral regions was the least affected accounting to 8.3% of this population. The majority of the study population presented with tetraplegia with incomplete lesions and paraplegia with complete lesions. These findings were similar to a study conducted in Spain, where the most commonly affected level was the cervical region (50.9%) with the most prevalent group being incomplete tetraplegia (29.8%) (Bárbara-Bataller, Méndez-Suárez, Alemán-Sánchez, Sánchez-Enríquez & Sosa-Henríquez, 2018). In another study done in Scotland, cervical injuries have also shown to be common, with 60.6% of TSCI resulting in cervical injury, which has increased over the years to 66.3% in 2013. The proportion of TSCIs with AIS C and D (incomplete injuries) has increased significantly from 19.7% in 1999 to 39.5% in 2013, whereas AIS A (complete) has decreased slightly from 32.7% in 1999 to 25.9% in 2013 (McCaughey et al., 2016). Similar findings for complete injuries were seen in Finland (31.7%), Iceland (39%), Italy (54.7%) and United states (48.7%) (McCaughey et al., 2016). Furthermore, in developed countries such as the United States, incomplete injuries have also increased from 46.4% to 51.3% over the years from 1970s to 2000 (DeVivo, Biering-Sørensen, New & Chen, 2011). The difference in

complete and incomplete injuries and local and international settings, could be correlated with the aetiology of the injuries sustained. In developed countries, there is an increase in injuries sustained by falls in the elderly population as opposed to violence in the younger population locally. High impact violence can cause greater harm to the spinal cord which can result in more serious impairments (complete injuries) whereas the increase in falls has been associated with low domestic falls in the elderly population, often resulting in less severe neurological impairments (incomplete injuries).

In South Africa, we face a great challenge with resources, poor access to specialised care and lack of preventable strategies for a SCI care, due to the lack of epidemiology studies within the country (Joseph et al., 2015). There is also no SCI register in South Africa, which means there is no track record of the incidence of this injury. Epidemiology on SCIs is slowly being investigated and revealed over the years (Joseph et al., 2015; Pefile, Mothabeng & Naidoo, 2019; Sothmann, Stander, Kruger & Dunn, 2015). In previous years, we were made to believe the incidence rate was 21 and 29 per million in Africa, and 13 per million in Botswana (which is situated in sub-Saharan Africa), which were much lower compared to a study done in 2015. In this study however, the incidence rate of TSCIs in South Africa was found to be among the world's highest, at 76 per million, compared to 61 per million in China, 58 per million in Portugal, 53 per million in Canada, 44 per million in Russia and 9.3 per million in Spain. Global rates are thought to be around 23 per million (Barbiellini Amidei, Salmaso, Bellio & Saia, 2022; Joseph et al., 2015; McCaughey et al., 2016). The most common causes for these injuries sustained were violence, car accidents, falls and sports-related injuries (Barbiellini Amidei, Salmaso, Bellio & Saia, 2022; Joseph et al., 2015; McCaughey et al., 2016; Nas, Yazmalar, Şah, Aydin & Öneş, 2015). The prevalence and causes of SCIs vary from developing and developed countries, indicating a huge need for the management of preventative strategies which is tailored specifically to each area.

Various studies have attempted to quantify statististics on the prevalence of SCIs, however issues were noted that could prevent a accurate estimation. There is no standardised assessment for SCIs across developed and developing countries (Madasa, Boggenpoel, Phillips & Joseph, 2020). Numbers are estimated from research studies that only cover a small area within the country, and these numbers could therefore either be a overestimation or underestimation and

not necessary a representation of the SCI population. Furthermore, its noted with local research issues such as only including those 18 years and older or only using government funded facilities leaves a gap in the research for those paediatric or private sector injuries (Joseph et al., 2015).

2.3. SCI Aetiology

Currently, the most common causes of TSCIs locally and internationally, are due to preventable causes such as MVAs, falls and violence. The main causes do however differ between South Africa and the world, as violence such as gunshot wounds and stab injuries are the leading causes of TSCIs (Joseph and Nilsson Wikmar, 2016; Madasa, Boggenpoel, Phillips & Joseph, 2020). Assault was the leading cause of TSCIs within two studies done in Cape Town in 2016 and 2018, followed by MVAs and falls. A high of 60.9% was reported for assault, 27.5% reported for MVAs and 10.3% for falls (Madasa, Boggenpoel, Phillips & Joseph, 2020). These findings align with the findings in Joseph et al. (2015) who reported 59% for assault, 26% for MVAs and 12% for falls. It further revealed that in the assault category, 52% of cases occurred as a result of gunshots and 33% due to stab wounds and 15% due to interpersonal violence with blunt trauma (Joseph et al., 2015). Males were predominantly found to sustain a TSCI compared to females, peaking the age bracket 18-29 years. More injuries were sustained in the summer and winter months, with 23% of injuries sustained on a Saturday and 6% on a Thursday. The proportion of gunshot and stab wounds seem to be unique problem in South Africa compared to other countries. These gunshot injuries cause significantly more damage which often results in significant complications and an increase in acute hospital stay (Joseph, Scriba, Wilson, Mothabeng & Theron, 2017), which puts a big financial burden on the healthcare system and places considerable emotional, physical and psychological stress on the patient and their families.

The major causes for TSCIs in North America, Western Europe and Australia have been found to be four-wheeled MVAs (40%) whereas in South-east Asia two-wheeled and non-standard vehicles were more predominant (47%) (Cripps et al., 2011). Car accidents tend to be the leading cause of TSCIs in developed countries whereas falls tend to be the leading cause in some developing countries (Chiu et al., 2010). This was evident in a study done in The United States, that found the common aetiologies to be MVAs (31.5%), followed by falls (25.3%) and gunshot wounds (10.4%) and 78.3% were reported to be males. MVAs were the leading cause

for TSCIs in the 45-year age bracket, whereas falls were the leading cause in the over 45-year age bracket (Chen, Tang, Vogel & DeVivo, 2013). A recent study in China reported the most prevalent causes of TSCIs to be falls (55.2%), MVAs (26.5%) and strike injuries (10.1%), with a male to female ratio of 1.62:1 and 50.3% and 49.7%, respectively (Jiang et al., 2022). Similarly, a study done in Switzerland found falls to be the main problem (37.1%), followed by sports and leisure (26.5%) and MVAs (22.9%), with more men (74.4%) affected than females (25.6%) (Chamberlain, Meier, Mader, Von Groote & Brinkhof, 2015). Increasing injuries related to falls have been associated with the older population due to tripping or balance difficulties, and younger injuries related to falls from a height due to occupation or falling out of trees. While the increased MVAs incidents in developed regions could be due to poor traffic laws and compliance, driving under the influence and disregarding seat belt regulations could also attribute to the increase in MVAs causation. High crime areas, gang-related violence, high unemployment rates, domestic abuse or alcohol and drug-related influence could be possible contributing factors for the high percentages seen locally for causes of TSCIs.

The research presented indicates that SCI causation varies in developed and developing countries and suggests that management and preventative strategies needs to be developed as per region. The variance in incidence and aetiology would indicate a need for a specific and and tailored preventative approach per region with joint collaboration implemented with the health, education and justice department (Madasa, Boggenpoel, Phillips & Joseph, 2020).

2.4. Mortality

It is well known that the survival rate in this population is significantly lower than in the able-bodied population (WHO, 2013). Literature has shown that over the past few years mortality rates during the first two years after sustaining a SCI have substantially declined by up to 40% due to improvements in medical management in the acute and critical care (DiMarco and Dawson, 2014; Madasa, Boggenpoel, Phillips & Joseph, 2020). Mortality rates vary across countries, with first-world countries reporting up to 80% survival rate 10 years post injury. These rates are however attributed to quality and efficient specialised care (Furlan, Noonan, Cadotte & Fehlings, 2011; Madasa, Boggenpoel, Phillips & Joseph, 2020). Research has shown that Greece reported an in-hospital mortality rate of 20%, and a similar finding in Botswana reported an in-hospital mortality rate of 20%, whereas a 0% mortality rate was reported in Sweden. These differences in findings could be attributed to TSCI management,

with Greece and South Africa following a non-specialised approach for care compared to Sweden (Madasa, Boggenpoel, Phillips & Joseph, 2020).

According to the WHO (2013), mortality rates for SCIs are five times higher than that of able-bodied individuals. Poor access to specialised medical health care, time taken for medical intervention and secondary complications are linked to high mortality rates for SCIs (Löfvenmark et al., 2015; Sisto and Evans, 2014). The increasing risk of mortality increases with severity and degree of neurological impairment; with higher mortality rates for cervical injuries (61%) and lower mortality rates with lower levels of injury (23% for lumber injuries and 14% for thoracic injuries) (Majdan et al., 2017). Mortality rates have also been shown to be much higher with complete lesions (p value ≤ 0.01) as opposed to incomplete lesions (Madasa, Boggenpoel, Phillips & Joseph, 2020). A mortality rate of 24% was reported in a local study at four years post TSCI (Madasa, Boggenpoel, Phillips & Joseph, 2020). South Africa is a developing country with high unemployment and crime rates, which lead to increasing violence-related injuries, which has become the leading cause of a TSCI and the second leading cause of death in South Africa (Madasa, Boggenpoel, Phillips & Joseph, 2020).

2.5 International classification of functioning, disability and health (ICF)

The impact of a SCI can be defined using the ICF, which is a universally recognised framework that conceptualises disability in relation to body structures and functions (impairments), activity, participation and contextual factors such as environmental and personal factors (WHO, 2013). It is a framework that is used by healthcare professionals to understand the impact of disability and functioning in relation to a health condition. The ICF recognises that individuals will respond differently to disability due to the impact of environmental and personal contributions or challenges, and that all these items defined in the framework are interconnected and influence each other (WHO, 2002). The ICF can be utilised as a starting point to assist with defining problems associated with disability and functioning within the SCI community (Cieza et al., 2010). This conceptual model provides a basis for understanding and managing disease, and as such will be utilised as the framework for this study. The components that were highlighted and explored for this study were: impairments (secondary complications), activity (functional independence: Spinal Cord Independence Measure- Self-report) and activity/participation (physical activity). The figure 2.1 below is a visual representation of the ICF domains described above.

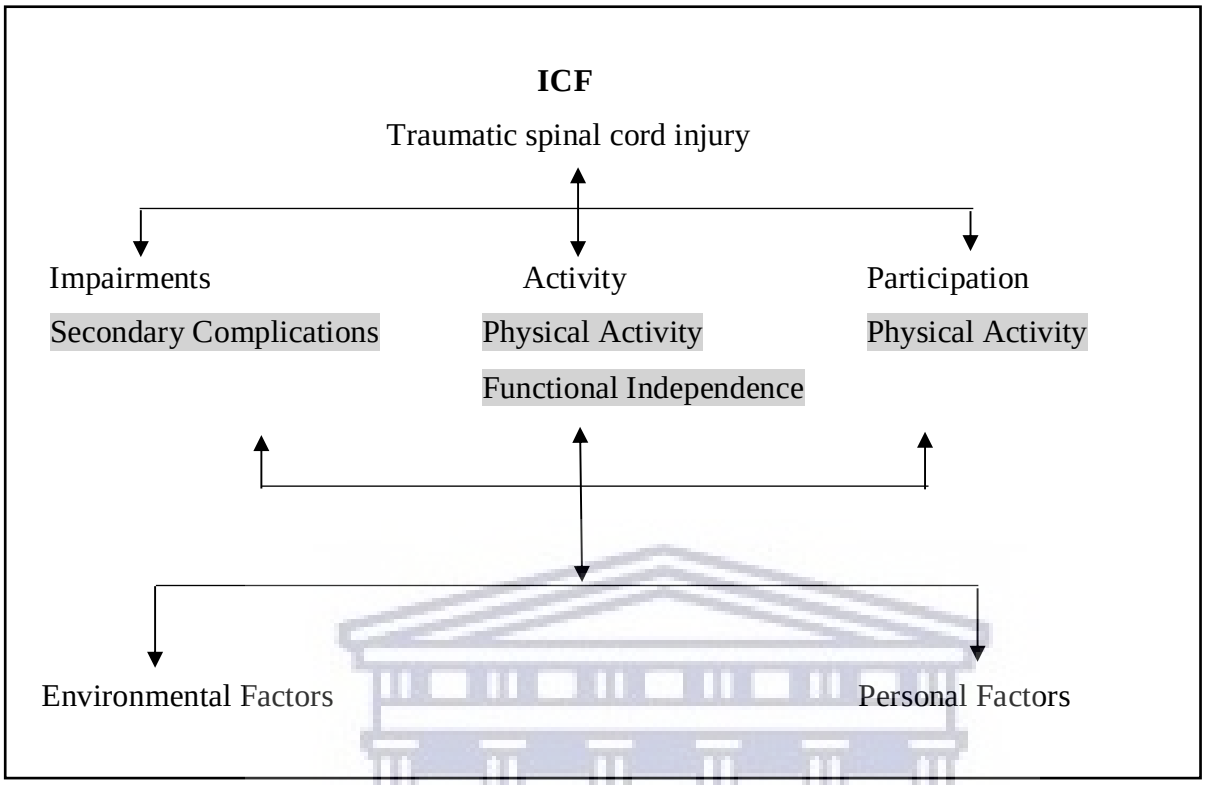

Figure 2.1 ICF

2.5.1 Secondary complications

The relationship between the health condition, body systems and structures, function and PA is demonstrated in the ICF (Suttiwong, Vongsirinavarat, Chaiyawat & Vachalathiti, 2015). Secondary complications form part of the impairments post injury. Damage to the spinal cord results in the impairment of several bodily functions and systems, which has a devastating impact on the lives of the individual and their family. It is common that people with disabilities and PwSCIs are more vulnerable to developing secondary complications. Research has shown that PwSCIs are more susceptible of getting the same chronic diseases such as diabetes, stroke and heart disease like the general population, due to premature ageing (Bauman and Spungen, 2008; Myers, Lee & Kiratli, 2007; Wahman et al., 2010). Research has further found that the risk of these chronic diseases is related to changes in body composition, due to decreased muscle mass and activity and, decreased PA, as a result of paralysis. In a study done by Cragg, Noonan, Krassioukov & Borisoff (2013), the prevalence of stroke among the SCI participants was 5.7% compared to 1.1% in the able-bodied participants. Similarly, PwSCIs prevalence of heart disease was 17.1% and 4.9% for able-bodied participants. The aforementioned study therefore showed that the prevalence of stroke

and heart disease was higher for SCIs compared to able-bodied people. As previously noted, PwSCIs have a higher risk of developing secondary complications and this has been found to be the leading cause of death for this population in lower income countries (Sisto and Evans, 2014; WHO, 2013). A study conducted in Cape Town, by Joseph and Nilsson Wikmar (2016) found that 26% in a sample size of 145 participants presented with one secondary complication, 17% with two and 8% with three and more secondary complications during acute hospitalisation. The most common complication was pressure ulcers (29.8%), followed by pulmonary complications (23.4%), and UTIs (17%). Pressure ulcers have been found to be a common complication in the acute stage after sustaining a SCI (Frielingsdorf and Dunn, 2007; Joseph et al., 2015). As seen from the literature, secondary complications are found to be highly prevalent and a possible factor related to mortality. The extent of secondary complications depends on the level of the injury sustained and the associated neurological fallout, with higher levels and completeness of injury more susceptible to developing secondary complications. Thus SCI rehabilitation programs are an essential requirement to promote functional recovery and independence with daily activities (Eitivipart et al., 2022; Madasa, Boggenpoel, Phillips & Joseph, 2020).

The prevalence of secondary complications, namely autonomic dysreflexia, pressure sores, heterotopic ossification, obesity, pain, bladder and bowel problems, muscle spasms, cardiovascular or respiratory disorders and assistance with ADLs has shown to increase as the years after injury increases (Liem, McColl, King & Smith, 2004). Pain was found to be very difficult to manage, more so than sensory and motor loss. High levels of pain were closely correlated to increased depression, increased anxiety, sleep disturbance and poor quality sleep (Norrbrink Budh, Hultling & Lundeberg, 2005). In a recent study done locally, with 55 TSCI participants, 89% reported at least one complication, and more than 70% reported four or more complications. The most common problem reported was pain (80%), followed by muscle spasms (76%), sleeping problems (56%), and bladder dysfunction (44%) (Madasa, Boggenpoel, Phillips & Joseph, 2020). As noted from these local studies we can see that more complications were reported with the participants within the community compared to the acute setting.

Similarly, in a study done in Australia, with a sample size of 70 participants, 93% of the participants complained of chronic pain of which 51% of the participants further reported the pain being distressing (Craig et al., 2013). Being able to identify the type of pain and

characteristics of the presenting pain, allow for identifying the appropriate management. Furthermore, it is imperative that the need for health promotion and the encouragement of PA be recognised since it has been found to decrease secondary complications associated with a SCI (Fekete and Rauch, 2012; Kehn and Kroll, 2009).

2.5.2 Activities of daily living

It is recommended to perform ADLs throughout the day to allow for movement and decrease the time spent in SED. Thus, engaging in 10-min periods of PA throughout the day may be more realistic than a single 30-minute period of PA and ultimately, engagement in minimal PA is better than none (Bull et al., 2020). For those with SCIs, issues such as being unable to move or move in a wheelchair, loss of sensation, paralysis of the sphincters with involuntary urination or defecation and changes with sexual function cause major challenges for PwSCIs. Independence with ADLs such as preparing and eating food, dressing or undressing, washing the body or daily grooming, controlling bladder or bowel and mobility can be assessed by healthcare professionals to determine the physical ability and functional ability of individuals (Szeliga, Brzozowska-Magoń, Borys, Wolan-Nieroda & Walicka-Cupryś, 2022). A study done by Möller et al. (2021) which used the Spinal Cord Injury Measure-Self-report to determine functional ability, reported a mean of 12.92 for tetraplegia (C6-T1), 16.16 for paraplegia (below T1) and a total score of 13.36 within the self-care subscale. For the respiration and sphincter management subscale, a mean of 26.24 for tetraplegia (C6-T1), 27.15 for paraplegia (below T1) and mean total score of 25.65 were reported. Mobility subscale mean scores were 20.97 for tetraplegia (C6-T1), 20.48 for paraplegia (below T1) and a mean total score of 18.64 for this subscale. The overall total mean scores were 61.57 for tetraplegia (C6-T1), 64.66 for paraplegia (below T1) and 58.80 for the total mean score. These findings show that these participants reported more independence within the self-care subscale, just above average independence within the respiratory and sphincter management subscale and the least independence reported with the mobility subscale.

Similar findings were seen in another study that reported the mean score of 12.9± 5.8 for self-care subscale, 27.7± 7.8 for respiratory and sphincter management subscale, 14.1± 6.1 for mobility subscale and 54.9± 18.5 for the total score. These findings indicate a remarkable

difficulty experienced within the mobility subscale domain, showing less independence with this domain (Osterthun et al., 2020). Self-care subscale and the respiration and sphincter management subscale seem to be the domains that participants display better independence as opposed to the mobility subscale. Similar findings were seen in a more recent study that reported for the TSCI group, a median score of 18.0 for self-care subscale, 31.0 median score for respiratory and sphincter management subscale, 20.0 for mobility subscale and 69.0 median was reported for the total score (Majamäki et al., 2022).

It is evident from these studies noted that PwSCIs who have complete quadraplegia experience more difficulties with functional independence than those with paraplegia or incomplete lesions. Thus showing more independence with upper limb activities and poor functional mobility with lower limb activities. Other factors such as small group size, age and time since injury all influence participants functional ability within their daily acivities (Majamäki et al., 2022; Möller et al., 2021).

2.5.3 Physical activity

Maintaining an active lifestyle can be challenging, especially for PwSCIs who often lead sedentary lifestyles (Mat Rosly et al., 2018). The recommended guideline for improved health benefits, general fitness and functional abilities for the SCI population is to engage in moderate to vigorous aerobic exercises and resistance exercise training, which fall within the classification of leisure time physical activity (LTPA) (Eitivipart et al., 2022; Mat Rosly et al., 2018). LTPA has been classified as activities completed within an individual's free time, and comprises of sports or exercise participation, recreational activities or planned upper body moderate to vigorous activities. Furthermore, research has shown that no more than 52% of the SCI population engage in these activities (Eitivipart et al., 2022; Mat Rosly et al., 2018). According to the WHO guidelines, adults with disabilities should engage in at least 150-300 minutes of moderate intensity PA or 75 minutes of vigorous intensity PA per week to have beneficial outcomes (Bates et al., 2022; Bull et al., 2020). PA is categorised by different intensities, frequencies or step counts (Ainsworth et al., 2000; Park et al., 2021; Veerubhotla, Hong, Knezevic, Spungen and Ding, 2020).

PA is defined as any body movement produced by one's muscles that results in EE (Martin Ginis et al., 2018). EE is measured in kilocalories and the amount of expenditure relates to the

amount of muscle mass in the body as well as the intensity, duration and frequency of muscle activity. Furthermore, calorie expenditure of PA differs from person to person based on body composition, age, physical fitness, sex, mechanical efficiency and environmental conditions at which the activities are performed. Research has also shown that EE related to body weight has increased three to four times during non-exercise PA compared to sedentary behaviour for motor complete tetraplegia and up to six times with exercise activities (Holmlund, Ekblom-Bak, Franzén, Hultling & Wahman, 2019).

The metabolic cost of resting is indicated as 2.7 mL/kg/min for SCIs, which is the normal rate for 1 metabolic equivalent (MET) (Ainsworth et al., 2000; Park et al., 2021; Veerubhotla et al., 2020). Based on how much energy is used during daily PA, in multiples of 1 MET, an intensity rating is assigned to that activity. Thus, according to MET values, intensities of activities can be described as: SED (1.0-1.5 METs), LIPA (1.6-2.9 METs), moderate to vigorous intensity/MVPA (>3 METs) (Ainsworth et al., 2000; Park et al., 2021; Veerubhotla et al., 2020). The metabolic rate increases as working effort increases (Veerubhotla et al., 2020).

In previous literature, most of these studies assessed PA with questionnaires, as these are inexpensive and easy to administer. Questionnaires do however have limitations, as it is generally subjective in nature and the results rely solely on the participants' memory and interpretation (García-Massó et al., 2013; Valanou, Bamia & Trichopoulou, 2006). Other methods used to determine PA by means of assessing EE, is accelerometry. These have shown to be inexpensive, accurate and discreet (wearable devices) enough to be used during daily living. In recent decades, accelerometers have been widely used and validated in many studies. The accelerometer objectively measures PA in terms of intensity, frequency and duration of the activity, and this is summarised in terms of counts. Specific cut-points are used to determine intensity levels. In a study done by Holmlund et al. (2019) they determined the cut-points for moderate-to-vigorous PA as >9515 vector magnitude counts per minute (VMC) for paraplegics and > 4887 VMC/min for tetraplegics. It revealed excellent accuracy (AUC > 0.9) for paraplegics and good to excellent accuracy (AUC>0.8 and AUC >0.9) for tetraplegics. While ambulant participants cut points were 8829 VMC/ min for male moderate PA and 9365 VMC/min for female moderate PA while 12482 VMC/min for males vigorous PA and 20962 VMC/min for female vigorous PA (Bammann et al.; 2021). There are no previous studies done with ambulant SCI participants and these cut points for ambulant participants were derived from a study of older able-bodied individuals aged 59-73 years (Bammann et al.; 2021). PA

intensity refers to the rate of METs, which are determined by the ratio of a working metabolic rate as it relates to the resting metabolic rate. PA is categorised by different intensities, frequencies, step counts and type/mode, namely: SED, LIPA and MVPA (Bates et al., 2022).

2.5.3.1 Sedentary Behaviour (SED)

Despite the many benefits of PA, PwSCIs remain the most inactive, with only 13%-16% reporting being engaged in PA, whereas the majority reports no engagement with PA (Ginis et al., 2011; Murphy, Kratz & Zynda, 2019). As such, SED has been associated as a risk factor for poor health and increased risk of developing cardio-metabolic diseases (Bates et al., 2022). SED is characterised as any waking activities performed while in a seated or reclined position that result in an EE of ≤1.5 METs (Ainsworth et al., 2000; Bates et al., 2022; Gibbs, Hergenroeder, Katzmarzyk, Lee & Jakicic, 2015). Activities, such as time spent in a seated position, watching television, seated administrative tasks at work/working at the computer, reading, standing, continue to be classified as SED patterns (Ainsworth et al., 2000; Veerubhotla et al., 2020).

In a study done in the United States, participants were required to do a range of different tasks such as: resting while sitting in a wheelchair, watching television, working at a computer, sweeping the floors, loading and unloading a dishwasher, wheelchair propulsion at slow/normal/fast pace, w/c propulsion on a slope, theraband exercises and playing basketball. All activities were recorded, and each participant performed each activity for a period of 10 min, which followed with a 3- min break afterwards. The cut-points between SED and LIPA were 2.433 counts per minute (CPM) and 12.467 CPM between LIPA and moderate intensity. The study also reported 37% time spent in SED, 39% time spent in LIPA and 24% time spent in MVPA. It also noted that the results from their study would possibly differ from those within the community, where SED seems to be more prevalent within the SCI community (Veerubhotla et al., 2020).

In another study conducted in Thailand, 49% of the study group were classified as sedentary with a higher percentage seen in the over 30s age group (more than 50%) and those with a longer time since their injury (more than 55% with injuries 6 years and older). The average time spent per week in mild intensity LTPA was 4.7± 18.4 and 132.0± 254.3 for moderate to heavy intensity (Eitivipart et al., 2022). Prolonged SED is closely associated with developing secondary complications and can be a risk factor for mortality among the SCI

population. Understanding the impact of perceived barriers to PA could broaden our understanding of poor adherence to PA within the communities, however these may not be generalized to all regions and countries. Geographical locations, climate and weather conditions, cultural factors, economic status or SCI policies are elements that could possibly affect engagement in PA within the community (Eitivipart et al., 2022).

2.5.3.2 Light intensity PA (LIPA)

Light intensity activities require minimal effort compared to MVPA and are defined as activities that result in EE <3 METs (Ainsworth et al., 2000; Collins et al., 2010; Veerubhotla et al., 2020). Examples of LIPA in everyday life include activities such as slow walking (inside the home, walking in an office at work, grocery shopping); multiple household tasks requiring light effort (i.e., making the bed, sweeping the floors, dusting, eating and preparing food, hairstyling) or w/c propelling on tiles (Ainsworth et al., 2000; Collins et al., 2010; Veerubhotla et al., 2020). EE for different tasks varies for those of the able-bodied population, children or adolescents, as well as for complete and incomplete SCIs, due to the differences in physiological and anatomical characteristics.

In a cross-sectional descriptive study done by Warms, Whitney and Belza (2008), the mean daily hours reported was 9.1 (SD: 1.96) spent in bed/sleeping, 12.5 hours (SD: 2.71) spent in LIPA, 1.3 (SD: 1.31) hours spent in moderate PA and 0.33 (SD: 0.45) spent in vigorous PA. These results indicated that these participants were not meeting the necessary recommended guidelines for PA, with most time engaged in LIPA and SED. The findings further revealed significant findings for the younger populations (t= 2.63, p=.012) showing that the younger age group being more active than the older group. This study and similary other studies that are objectively measuring PA, have small sample sizes and low numbes of female participants. It is important to interpret these findings with caution as the results may not be a true represenatation of the entire population. Type of wheelchair and the apporopiateness of the wheelchair within the different terrains is also something that could possibly impact the PA measurement.

2.5.3.3 Moderate to Vigorous Physical Activity (MVPA)

Adults with SCIs should exercise for at least 20 minutes twice a week at a moderate-vigorous intensity, as well as perform three sets of strength exercises for all major muscle groups at a moderate-vigorous intensity in order to obtain cardiorespiratory fitness and strength benefits (Martin Ginis et al., 2018). MVPA is defined as activities that result in an EE >3 METs (Ainsworth et al., 2000; Collins et al., 2010; Veerubhotla et al., 2020). Examples of MVPA include activities such as wheelchair propulsion up a slope/on carpets/ on grass, weight-lifting, resistance band exercises, dressing/undressing, vacuuming, basketball or table tennis (Ainsworth et al., 2000; Collins et al., 2010; Veerubhotla et al., 2020). In a study done by Park et al. (2021) with a study sample of 10 participants, participants were required to do a walking-assisted program with an exoskeleton. The MET peak results during the 6-minute walk test pre, mid and post training was 5.1± 1.3, 4.9± 0.7 and 4.9± 1.1, respectively. And the MET average results during pre, mid and post training was 3.3± 0.9, 3.5± 0.6 and 3.5± 0.7, respectively. These MET results were equivalent to MVPA and the participants walked a further distance at mid training (37.5± 10.5 m) than pre training (20.7± 5.5 m) and improved more with post training (49.1± 15.2 m) compared to pre and mid training. The results of this study showed that exercise with a robotic exoskeleton corresponds to MVPA. Exercising with exoskeletons allows individuals with lower limb paralysis to walk on the ground but it is expensive and not economically feasible for most healthcare systems. There is controversy about the use of exoskeletons, with some scholars saying it could be more harmfull for the PwSCIs mental wellbeing. It also steers the PwSCI away from gaining strength and independence within their seated functional positions (Park et al., 2021).

A study in Malaysia revealed that participants reported that they often engaged in leisure activities and light activities, presenting 48.6% and 12.9%, respectively while only 8.6% reported participation in moderate-vigorous activities thus revealing that 73% reported no engagement in any moderate-vigorous exercises (Mat Rosly et al., 2018). In addition, a longitudinal cohort study conducted in the Netherlands discovered that one-year post in-patient rehabilitation, PA increased from 88.7± 36.1 min/day to 116± 59.2 min/day and SED decreased from 732.4± 81.9 min/day to 665± 121.3 min/day. The increase in PA minutes was correlated to an increase in walking mobility in the community for ambulant participants, but still however revealing an alarming time spent in SED compared to PA. The study also found that the older population, and those with lower ambulation level and tetraplegia engaged in less PA and were

associated with increased SED (Postma et al., 2020). It is clear that different activities and tasks in daily life produce different EE, which are still largely unknown to PwSCIs and healthcare professionals alike. A need exists for health promotion to educate on the type of activities PwSCIs could perform daily that would be beneficial for them.

Furthermore, it is important to note that all of these studies mentioned above, were completed in developed countries. The outcome within these deveopled settings showed low participation with PA and we can possible expect PA to be lower within our more local settings due to poorer economic status and fewer available resourses.

2.6 Summary

The above chapter presented the research available for TSCIs, secondary complications, functional independence and PA. The ICF was used as the conceptual framework for this study, and it was utilised to provide structure to explain how PwSCIs are affected by the injury and how it impacts their PA. To date there is very limited research that measures PA objectively, especially for the SCI population in Cape Town, South Africa. Research in this regard and information obtained from this study will prove to be invaluable.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

In this chapter, the research setting, namely the Cape Metropole in the Western Cape, South Africa, an overview of the study and a rationale for the methods used in the study are discussed. The research questions that guided the study are followed by a description of the participants. Each aspect is explored and described in detail. In addition, the methods of data collection and data analysis are presented. Finally, all ethical considerations and ethical principles related to research on human interaction are clearly provided and explained.

3.2 Research setting

This study was conducted in the Cape Metropole region in the Western Cape, South Africa. The Western Cape is one of nine (9) provinces in South Africa, situated on the south-western coast of the country. It is the fourth largest province, with approximately two-thirds of its population living in the Cape Metropole region. This area, of approximately 2446km^2 has a population rich in cultural diversity. The Cape Metropole stretches from Gordons Bay to Atlantis and includes the suburbs of Mitchells Plain and Khayelitsha (City of Cape Town, 2021). According to the City of Cape Town's 2021 socio-economic profile, the population is estimated at 4.76 million people (City of Cape Town, 2021), with a population density of 1915 people per square km. This district has two tertiary hospitals providing acute care for TSCIs, namely Groote Schuur Hospital (GSH) and Tygerberg Hospital. GSH is the only facility, which has a specialised SCI unit providing acute care for TSCI individuals in the Western Cape (Sothmann, Stander, Kruger & Dunn, 2015). Due to limited resources (number of beds/placements) available, patients are admitted to these hospitals on a referral basis (Joseph et al., 2015). Limited information is available on the continuum of care post discharge from the acute setting, or whether patients are further managed at their local primary/ community health care centres in the community. Furthermore, physiotherapy rehabilitation services are not available at all primary health care facilities. As noted in the City of Cape Town's socio-economic statistics of 2021, there are 126 clinics, 31 mobile clinics, 47 community day care facilities and 8 district hospitals based within the Cape Metropole region (City of Cape Town,

2021). Specialised rehabilitation is offered at Western Cape Rehabilitation Centre (WCRC), but patients are seen here on a referral basis and only patients who demonstrate the best propensity for recovery are accepted (Joseph et al., 2015). Figure 3.1 below presents the Cape Metropole region.

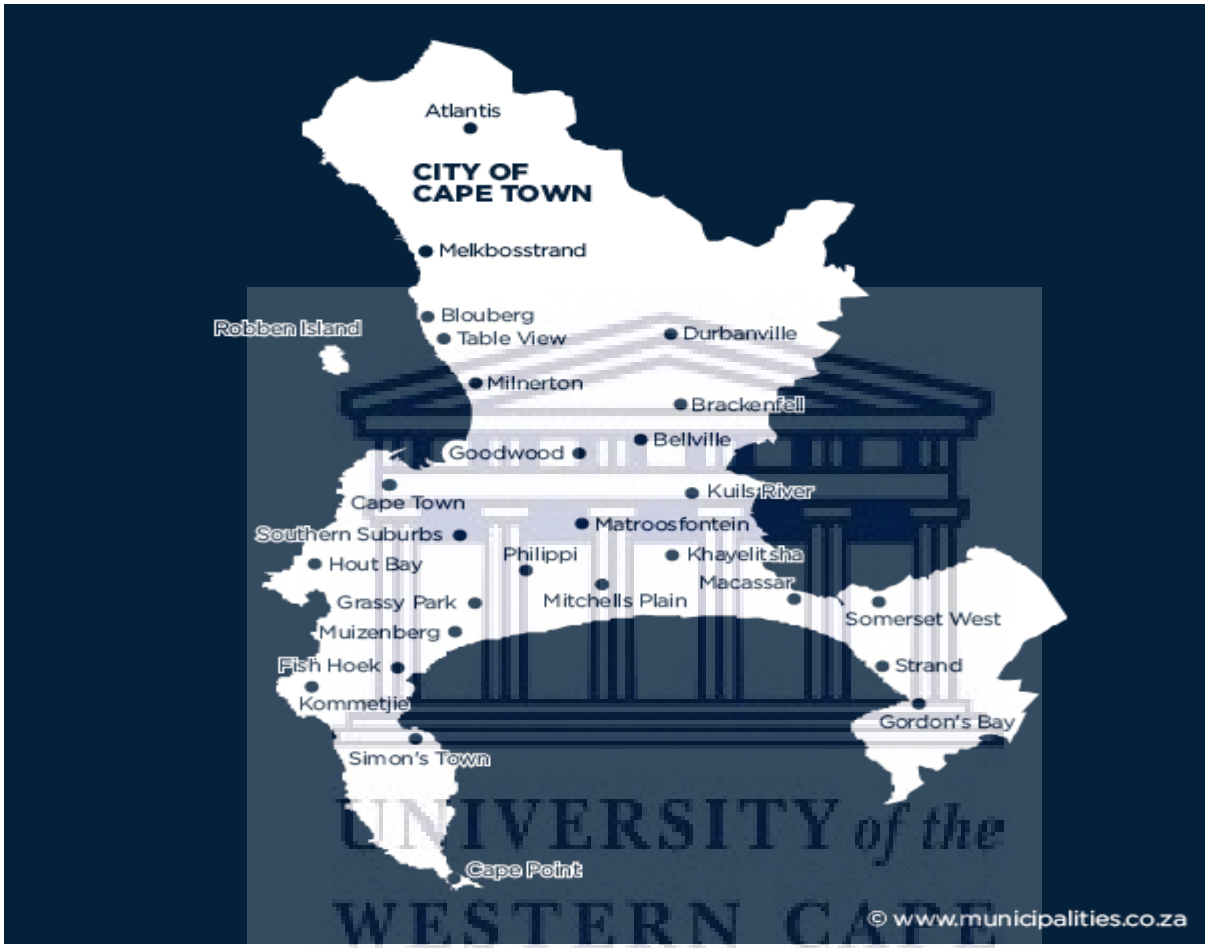

Figure 3.1 Cape Metropole

3.3. Research Design

A quantitative cross-sectional design was utilised and all community- dwelling adults with TSCIs who met the inclusion criteria; those discharged from GSH between 2016 and 2020, were included. These studies are generally observational in nature and allows the researcher to draw evaluations in a natural setting, without any intervention. The measures are assessed at a single point in time and this design has shown to be useful in determining prevalence and associations between variables. Cross-sectional studies require less time to set up and it is able

to analyse multiple variables within a time point (Caruana, Roman, Hernàndez-Sànchez & Solli, 2015; Mann, 2003). A cross-sectional design is grounded within the positivist paradigm, where the origin of "truth" is known and associations with the outcome are sought for possible intervention and mediation. Therefore, the researcher's position was that PA is influenced and moderated by secondary complications and functional limitations, which if addressed, could optimise PA. However, the cross-sectional design is limited in explaining the direction of the relationship between exposures/risk factors and outcome.

3.4. Study population

The study population consisted of all individuals who sustained a TSCI, who were 18 years or older, and reside in the Cape Metropolitan region in the Western Cape. The target population was community- dwelling persons with a TSCI who were discharged from GSH post-acute care, and were residing in the community for at least one-year post injury. The inclusion criteria further included (1) confirmed TSCI, including cauda equina and conus medullaris lesions; (2) TSCIs with lesions C6 and below (participants who will be able to manually mobilise with their wheelchair); (3) those admitted to GSH for acute SCI care during the years 2016-2020; and (4) all participants consenting to the study. TSCI participants who presented with other neurological impairments or severe cognitive deficits that prevented them from providing consent or the ability to respond to relevant testing, were excluded from the study.

3.5. Sampling

Participants were sourced from the SCI database of GSH for the years 2016-2020. They were retrospectively identified at the D15 ward and physiotherapy department at GSH. Contact was made with administration at the records department to locate the necessary folders. This available pool consisted of 403 people who sustained a TSCI for the years 2016-2020. Participants were then selected based on the inclusion-exclusion criteria, accounting for 297 people. From the 297 people who met the inclusion criteria, 76 participants were included. Importantly, these 76 persons with TSCI were reached via contact details provided to the hospital during their acute stay. A large proportion (214 of 297) could not be reached via their contact details, 10 relocated to other areas and provinces in South Africa, and 2 declined to participate in the study. The final sample was deemed sufficient to study several risk factors for PA (Al-Habib et al., 2011). However, the number of risk factors needed to be minimised,

as seen with the pre-selected stratified analyses, to ensure sufficient power of analysis. The figure 3.2 below presents the study population and sampling described above.

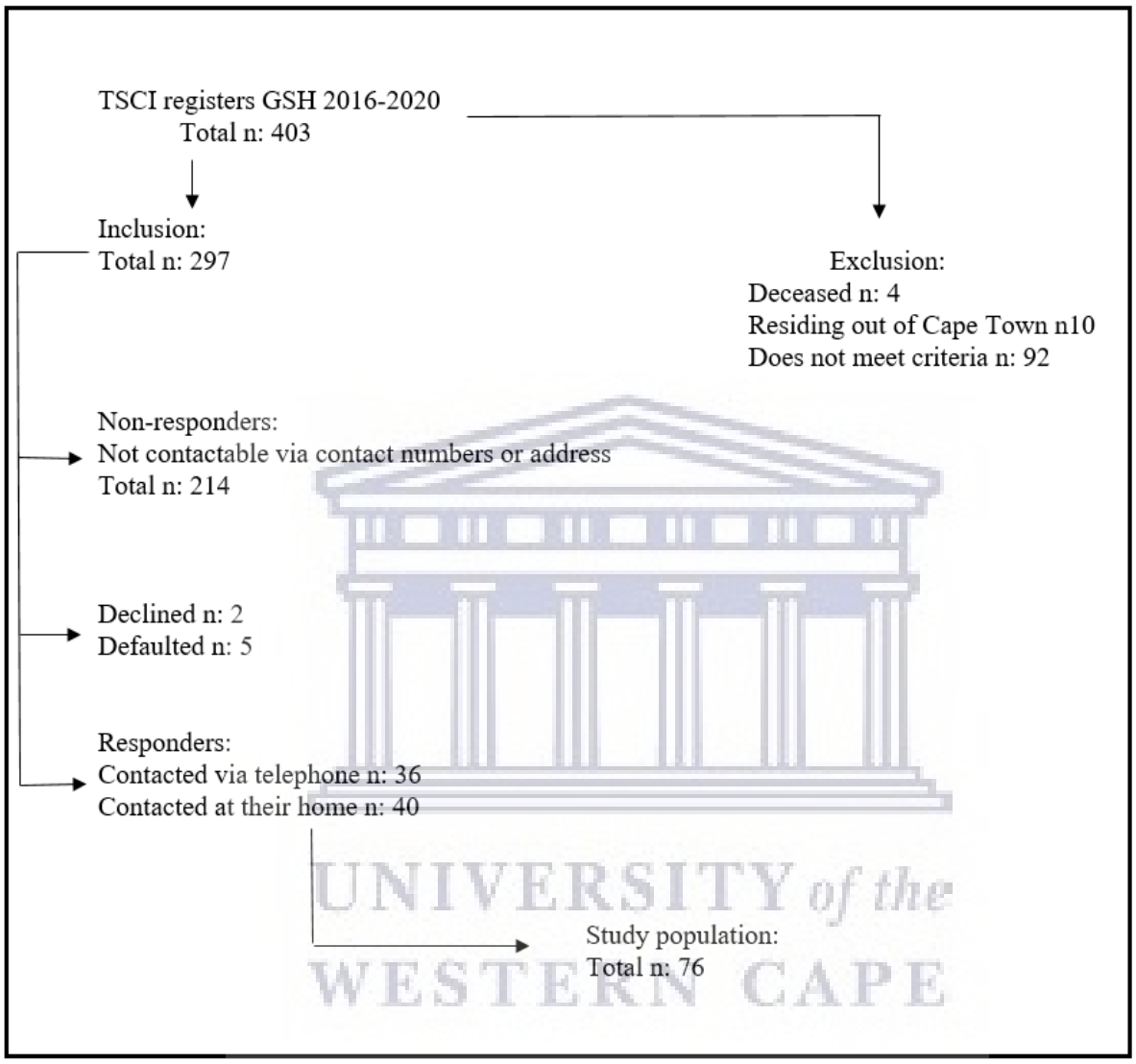

Figure 3.2 Study population and sampling

3.6. Research instruments and Conceptual Framework

Selection of the measures was inspired by the ICF, where the main outcome, objective PA behaviour, is seen as an objective performance indicator of the concept physical *participation* in the conceptual model. Based on this framework variables and instruments were selected on the level of impairment (e.g., disease severity, health status, secondary complications) and activity (functional status) as well with the aim of assessing their influence (as covariates) on PA. For more details on the framework used in this study, refer to Appendix 8.

3.6.1. Socio-demographic and Injury characteristics (epidemiological profile)

The socio-demographic and injury characteristics were assessed using the International Spinal Cord Injury Core Data Set version 2.0 (Appendix 9) for socio-demographic characteristics. The instrument is descriptive in nature and has been developed by an expert Delphi panel, further ensuring face and content validity of the tool (DeVivo et al., 2006). The assessment tool comprises of thirteen (13) questions that report data on the study population characteristics. It starts with including the date of assessment, birth date of the participant, date of injury, acute admission date and date of admission for rehabilitation (including the date of final in-patient discharge) and date of death. The tool also considers the participant's gender; which is divided into male, female, transgender and unknown. Injury aetiology is also included and separates aetiology into trauma and non-traumatic causes. Trauma causes noted were: sports injury, assault, transport, and falls. Whereas non-traumatic causes looked at birth injuries, congenital disorders, degenerative conditions, benign or malignant tumours, vascular conditions, infection and other non-traumatic or unknown causes. In addition to this information gathered, the tool also looked to obtain information on ventilator assistance, vertebral injury, any other associated injuries and spinal surgery. The answers to these questions were yes/no/unknown. The last question in this tool looked at the place upon discharge from acute setting/hospitalisation i.e., rehabilitation hospital, private home, nursing home, assisted living residence, group living situations with non-family members, hotel, homeless, other and unknown situations.

In addition to this questionnaire, a self-made questionnaire was developed in order to obtain additional information needed (Appendix 9). This tool included: 1) current residence 2) employment status at time of injury 3) current employment status 4) marital status and 5) highest educational level obtained.

3.6.2. Secondary complications

Secondary complications were assessed using the secondary health complications scale for SCI (Appendix 10). This tool focuses on secondary complications associated with SCI that directly or indirectly impact health and physical function. The assessment tool consists of 16 questions with the items selected based on the following three criteria: 1) that the items present conditions that are physiological in nature 2) that they are measurable by patient history or physical examination, reported episodes, validated scales, or medical tests and interventions and 3) those that are prevented or managed with medical intervention and health behaviours. Problems in

skin, musculoskeletal, autonomic nervous system, pain, bladder/bowel, and cardiovascular disorders are all represented by the items. The score rating scale used in this tool, is a 4-point ordinal scale ranging from 0 (not experienced or an insignificant problem) to 3 (moderate or significant problem). The total score is then derived from the sum of the ratings, and range from 0 – 48. The scores were then split into the prevalence of no-low problem and moderate-significant problem. The higher the score the more secondary complications experienced. This test has proven to be valid and reliable with internal consistency exceeding 0.76 and test-retest reliability ranges of 0.56-0.80 (Kalpakjian, Scelza, Forchheimer & Toussaint, 2007).

3.6.3. Functional status

Functional status was measured using the Spinal Cord Independence Measure - self-report (SCIM-SR) version 4 (Appendix 11). This is a subjective measurement, which assesses ADL function in self-care, respiration and sphincter management; as well as mobility and transfers, with a maximum score of 100. Four questions about self-care abilities, such as eating and drinking, washing upper and lower body, dressing upper and lower body; and grooming, were included in the first category. This component has a total value of 20, with the lowest score being 0 and the highest being 20. Four questions about respiratory, bladder and bowel function and toileting were included in the second category, with a total of 40 points. Participants were rated and scored according to the level of independence shown in this category and how much assistance was needed with breathing and bladder and bowel management. The final category is about mobility, and it consists of 9 questions with a total score of 40. The scores are ranked according to functional mobility, which includes the use of a wheelchair, if the individual is able to walk independently, as well as the usage of any assistive devices that help with mobility indoors and outdoors. The higher the scores the more independent the individual (Catz et al., 2001). This instrument has been shown to be valid and reliable with an intraclass correlation coefficient of 0.83 for the entire scale (Bluvshtein et al., 2011).

3.6.4. Physical activity and PA behaviour

PA was measured using an Actigraph wGT3X-BT accelerometer, which among other features, provides for the calculation of the vector magnitude sum of movement across 3 axes (Aadland and Ylvisåker, 2015). This small device measures the intensity and volume of active movement

objectively, in the form of activity counts summarised from bodily accelerations, where a higher score means more activity taking place (Yang and Hsu, 2010). The intensity of PA is defined by MET, which is calculated by the EE to the body mass of an individual. It is therefore important when assessing PA to measure EE. Accelerometry has been proven to be a cost effective and practical means of establishing EE, in large research studies, by means of relating it to counts (from SED to vigorous PA) (Bammann et al., 2021). The accelerometer cut-points that were used to analyse the raw data for wheelchair users and walkers are presented in table 3.1 below (Bammann et al., 2021; Holmlund et al., 2019).

Table 3.1: Physical activity behaviour: cut-points

Subgroup	Sedentary PA	Light-intensity PA	Moderate PA	Vigorous PA
Wheelchair users				
Tetraplegia	<2000 VMC/min	3462-4886 VMC/min	4887-9278 VMC/min	9279 VMC/min
Paraplegia	<2000 VMC/min	6997-9514 VMC/min	9515-13238 VMC/min	13239 VMC/min
Walkers				
Males	<2000 VMC/min	<8828 VMC/min	8829 VMC/min	12482 VMC/min
Females	<2000 VMC/min	<9364 VMC/min	9365 VMC/min	20962 VMC/min

These devices were sourced from the University of the Western Cape's Physiotherapy Department. Each participant was fitted with an accelerometer, to be worn for seven (7) consecutive days. The researchers would check in with the participants after a few days to see how they were managing, and if they needed any clarity with wear time or filling in the time sheet diary. The accelerometer is both reliable and valid with high test-retest reliability of >0.74 (Zbogar, Eng, Miller, Krassioukov & Verrier, 2016).

3.7. Data Collection procedure

Once ethics approval was obtained, data collection commenced. The research started by using a pre-existing SCI database from 2016, which was updated to the year 2020 by identifying patients admitted to D15 ward in the physiotherapy department of GSH. The list was given to the researchers involved in the study (two main researchers and one research assistant who was trained accordingly). Each researcher was given instruction to contact participants telephonically. Participants who could be reached telephonically were provided with an explanation of the study, and arrangements were made with them to meet at their homes at a time and day convenient for them. Participants were either contacted telephonically or located at their homes in the community. Before commencement of data collection, each researcher was given a checklist as a reminder for the procedure process when collecting data from participants. Each researcher used a logbook to keep track of the aliases being used and the devices that were signed out. The logbook also served as a reminder as to when to check in with participants on how they are managing with the device and when to collect the device. The Actigraph accelerometer was initialised using Actilife v6 software prior to the assessment. Each participants PA behaviour was tracked for a period of seven days. Each device needed to be charged sufficiently, before initialisation could be completed. Each device was initialised at a sample rate of 30 Hz. The date and time were set up and the alias, accelerometer device number, gender and location of the device (wrist or ankle) were entered into the program.

After being thoroughly informed about the study and any uncertainties addressed, written consent was obtained from the participants and the researchers proceeded with data collection. The questionnaire booklet took approximately 45 minutes to complete. Each booklet contained all the subjective measurement tools needed for data collection. Researchers proceeded with the first tool namely: International Spinal Cord Injury Core Data Set (version 2.0), followed by the SCI secondary conditions scale, and lastly, the SCIM-SR (version 4). The researcher thereafter proceeded to explain the use of the accelerometer, and placed it on either the wrist for wheelchair users (62 participants) or ankle for walkers (14 participants). Each participant was asked to complete a timesheet diary for seven (7) days, with the first day of data collection starting the day after assessment. Participants were asked to write down the time they put the accelerometer on in the mornings and the time they take it off before they sleep at night. They were informed to wear the device at all times but to remove the device when bathing or before any water activities (e.g., swimming), and when sleeping at night. The device was then

collected on day 9, allowing 7 days for data collection. After completion of data collection, the questionnaire booklet information was recorded into an Excel spreadsheet, and the data downloaded from the device.

3.8. Statistical Analysis (Data analysis)

Data was captured into an Excel spreadsheet for all outcome measures, summarised and visualised. Data was then coded and transferred to SPSS v.28 software for analysis. Demographic and injury characteristics were displayed using descriptive statistics and presented it using frequency tables and expressed in percentages. Descriptive statistics was used to summarize the secondary complications data and it was presented using frequency tables, while the differences in secondary complications for the subgroups were computed using the Fisher Exact test with p level set at 0.05. Furthermore, the functional indices were displayed using descriptive statistics and expressed in means and standard deviations. To determine the relationship between the variables, the student t-test was used with the p level set at 0.05 for significance.

The accelerometer data were downloaded using the Actilife 6 software and subsequently analysed. When downloading the data, an AGD file was created, and data were analysed in 60 sec epochs. This data was analysed according to each daily segment and presented as time spent in each intensity category. The cut-points retrieved from previous literature were used to classify intensity categories. The data was then presented as time spent engaging in SED/LIPA, Moderate intensity PA, and lastly, Vigorous intensity PA.

3.9. Ethics

Permission to conduct this research was obtained from the University of the Western Cape's Biomedical Research Ethics Committee BM19/7/2 and the GSH Research Board. All information about the study was made available, the procedure of the study was explained in detail and participants were then given the opportunity to consent to participate in the study. All questionnaires, information sheets and informed consents were available in three different languages to accommodate all participants, and researchers were fluent in English, Afrikaans and isiXhosa. Informed consent was obtained, and where written consent could not be provided, verbal consent was obtained via audio recording. All participants were assured that their participation in this study was completely voluntary and that their agreement, refusal or

withdrawal would not impact on the medical care they were receiving. The participants were informed that they could withdraw at any stage without any repercussions. Confidentiality of participants was maintained throughout the study. To ensure participants anonymity, the surveys did not contain information that may personally identify them. There was a low to moderate perceived risk with participation in the study, due to possible emotional distress that could arise during data collection. However, if the participants were affected by the study or experienced any emotional distress, appropriate referral to a counsellor for management was available. Participants were also compensated with a personal benefit for their participation in the study. All the data was stored on password-protected files on a computer. All participants' identification was replaced by a unique code, to which no unauthorised persons had access, to optimise confidentiality. Information obtained from participants was intended for the study only, and was treated with confidentiality. The raw data was stored in a locked cabinet in the principal investigator's office, and will be kept for a period of five years. The results of the study will be disseminated to the relevant parties.

CHAPTER FOUR

RESULTS

4.1. Introduction

In this chapter, the researcher presents and interprets the results of the study according to the objectives. Additionally, participant's injury characteristics as well as indices of secondary medical complications and functional abilities are presented. Objectively-assessed PA behaviour is also presented according to the methodological decisions made regarding cut-points.

4.2. Demographic Information

4.2.1. Socio-Economic information of participants

A total number of seventy-six (n=76) participants were recruited to take part in this study. The majority of the participants was male (88.2%) compared to females (11.8%), with ages ranging from 18 to 66 with a mean of 35.66± 10.93 (SD). According to this study, 67.1% completed primary education, while 25% completed secondary education. The aetiology of TSCIs were due to assault (64.5%), with a higher percentage for gunshot wounds (46.1%). With regard to injury level and severity, 52.6% had paraplegia and 50% were classified as having sustained a complete injury. More than half of the participants (64.5%) had no spinal surgery in acute management, with 71.1% sustaining vertebral injuries and 57.9% with associated injuries. Majority of participants sustained a TSCI approximately 3 to 6 years ago (77.6%), with a mean of 1.74± 0.44 for the total time since injury. Most participants (76.4%) are currently living at home with family support with a total of 73.7% currently single. Lastly, 65.8% of the participants were employed at the time of their injury, as compared to 84.2% who are now currently unemployed. The Table 4.1 represents the socio-demographic profile and Table 4.2 represents the injury characteristics of participants described above.

Table 4.1: Demographic characteristics of participants

Characteristics (n, %)	76	100
Gender (n, %)		
Male	67	88.2
Female	9	11.8
Age *(n, %)		
Mean (SD)	35.66 (10.93)	
Marital status (n, %)		
Single	56	73.7
Married	15	19.7
Divorced	3	3.9
Widow	2	2.7
Education (n, %)		
No schooling	2	2.6
Primary school	51	67.1
Secondary school	19	25
Tertiary school	4	5.3
Mode of mobility (n, %)		
Wheelchair	62	81.6
Walker with assistance	7	9.2
Independent	7	9.2
Employment status (at time of injury) (n, %)		
Unemployed	26	34.2
Employed	50	65.8
Current employment (n, %)		
Unemployed	64	84.2
Employed	12	15.8
Current residence (n, %)		
Home: Family	58	76.4
Home: Alone	3	3.9
Nursing Home	9	11.8
Assisted living residence	6	7.9

*Age as at 30 July 2022

Table 4.2: Injury Characteristics of participants

Injury Characteristics (n, %)	76	100
Level of injury (n, %)		
Paraplegic	40	52.6
Quadriplegic	19	25
Central cord	17	22.4
AIS (motor-sensory severity) (n, %)		
A	38	50
B	2	2.6
C	17	22.4
D	19	25
Aetiology (n, %)		
Gunshot wounds	35	46.1
Motor vehicle accident	22	28.9
Stab	14	18.4
Falls	3	3.9
Diving	2	2.7
Vertebral injury (n, %)		
Yes	54	71.1
No	17	22.4
Unknown	5	6.5
Associated injury (n, %)		
Yes	44	57.9
No	32	42.1
Spinal surgery (n, %)		
Yes	27	35.5
No	49	64.5
Time since injury (n, %)		
1- 2 years	17	22.4
3- 6 years	59	77.6

*time since injury as at 30 July 2022

4.3. Secondary complications

4.3.1 Secondary complications for the entire sample

Most of the participants 98.6% reported one or more secondary complication. The most common secondary complications were muscle spasms 86.8% (n= 66) and joint or muscle pain 72.4% (n= 55). The mean number of total scores for the complications were 19.18± 7.30. The complications, moderate-severe severity rating, and total mean scores are presented in Table 4.3 below. Furthermore, Table 4.4 presents the number of complications reported by participants.

Table 4.3: Secondary complications: Prevelence of moderate-significant problems

Secondary Complications (n, 76)	Moderate- significant problem (n %)
Period - prevalence of complications	
Muscle spasms	66 (86.8)
Joint or muscle pain	55 (72.4)
Bowel dysfunction	47 (61.8)
Chronic pain	45 (59.2)
Bladder dysfunction	42 (55.3)
Circulatory problems	37 (48.7)
Injury due to LOS	37 (48.7)
Autonomic dysreflexia	34 (44.7)
Sexual dysfunction	33 (43.4)
UTIs	30 (39.5)
Postural hypotension	28 (36.8)
Pressure sores	18 (23.7)
Contractures	14 (18.4)
Respiratory problems	11 (14.5)
DM	4 (5.3)
Heterotopic bone ossification	2 (2.6)

Table 4.4: Number of complications

Number of complications	
Patients with no complications	1 (1.3)
Patients with 1 complication	1 (1.3)
Patients with 2 complications	9 (11.8)
Patients with ≥ 3 complications	65 (85.5)
Total Scores (range 0-48)	**19.18± 7.30**

4.3.2 Secondary complications stratified by mobility status

As shown in Table 4.5 below, muscle spasms were reported by both wheelchair users and walkers, as a moderate-severe problem present in 88.7% (n=55) and 78.6% (n=11), respectively. This was followed by joint or muscle pain that was reported by 74.2% (n=46) of wheelchair participants and 64.3% (n=9) of walking participants. Concerning injuries due to loss of sensation, a significant difference was found between wheelchair users (p=.006) and walkers. No other significant findings were noted.

Table 4.5: Secondary complications and wheelchair users/walkers

Complication	wheelchair users n=76 (%)	walkers n=76 (%)	Fisher Exact Test
Muscle spasms	55 (88.7)	11 (78.6)	1.027 (.380)
Joint or muscle pain	46 (74.2)	9 (64.3)	.561 (.514)
Bowel dysfunction	40 (64.5)	7 (50)	1.020 (.368)
Bladder dysfunction	36 (58.1)	6 (42.9)	1.068 (.377)
Injury due to LOS	35 (56.5)	2 (14.3)	**8.128 (.006)**
Chronic pain	35 (56.5)	10 (71.4)	1.061 (.376)
Circulatory problems	33 (53.2)	4 (28.6)	2.779 (.140)
Autonomic dysreflexia	27 (43.5)	7 (50)	.192 (.769)
Sexual dysfunction	29 (46.8)	4 (28.6)	1.540 (.248)
UTI	26 (41.9)	4 (28.6)	0854 (.546)
Postural hypotension	25 (40.3)	3 (21.4)	1.752 (.232)
Pressure sores	16 (25.8)	2 (14.3)	.839 (.497)
Contractures	13 (21)	1 (7.1)	1.453 (.445)

Respiratory problems	10 (16.1)	1 (7.1)	.745 (.678)
DM	4 (6.5)	0	.953 (1.000)
Heterotopic bone ossification	2 (3.2)	0	.464 (1.000)

P<.05

4.4. Spinal Cord Independence Measure- Self report: functional abilities

4.4.1 Subscale: Self-care

The SCIM-SR measure is divided into three subscales, namely self-care, respiratory and sphincter management and mobility. Participants were asked about their daily functioning and management in each subscale. The minimum and maximum values are presented as 0-3 for all questions, except the questions on the ability to dress upper and lower body, which have a maximum of 4. The highest mean (3.04± 1.62) was for the ability to dress the upper body, while eating and drinking with or without assistance scored a mean of 2.63± 0.92, representing the second highest score. The total mean score for the self-care subscale was 15.03± 6.95. The questions, minimum and maximum values and mean of the Self-care subscale is presented in table 4.6 below.

Table 4.6: Self-care subscale

Questions (n=76)	Min - Max	Mean ± SD
Eating and drinking (with or without assistance)	0 - 3	2.63 ± 0.92
Ability to wash upper body	0 - 3	2.34 ± 1.14
Ability to wash lower body	0 - 3	1.86 ± 1.29
Ability to dress upper body	0 - 4	3.04 ± 1.62
Ability to dress lower body	0 - 4	2.62 ± 1.73
Grooming (with or without assistance)	0 - 3	2.50 ± 1.05
Self-care Subscale Total	**0 - 20**	**15.03 ± 6.95**

4.4.2. Subscale: Respiratory and sphincter management

The highest mean score was for respiratory function and bowel management. The means are represented as 9.89± 0.45 and 6.80± 2.29, respectively. The total median score for this subscale was 25.50, with a IQR of 18. The questions, minimum and maximum values and median of the Respiratory and sphincter management subscale is presented in table 4.7 below.

Table 4.7: Respiratory and sphincter management subscale

Questions (n=76)	Min - Max	Mean ± SD
Ability to breathe independently (with or without assistance or devices)	8 - 10	9.89 ± 0.45
Bladder management (independence or with assistance)	0 - 15	6.76 ± 6.16
Bowel management (independence or with assistance)	0 - 10	6.80 ± 2.29
Ability to use the toilet	0 - 5	2.84 ± 2.18
Respiratory and Sphincter Management Subscale Total	**10 - 40**	**Median 25.50; IQR 18**

4.4.3. Subscale: Mobility

The highest mean score was for bed mobility and inside mobility. The means are represented by 4.79± 1.96 and 2.55± 2.10, respectively. The total mean score for this subscale was 16.46± 9.90 and the overall total score mean was 57.22± 23.4; i.e., all three subscales combined with a composite maximum score of 100. The questions, minimum and maximum values and mean of the Mobility subscale is presented in table 4.8 below.

Table 4.8: Subscale: Mobility

Questions (n=76)	Min - Max	Mean ±SD
Ability to do bed mobility	0 - 6	4.79 ± 1.96
Ability to transfer from bed to wheelchair	0 - 2	1.43 ± 0.81
Ability to transfer from wheelchair to toilet/bath	0 - 2	1.17 ± 0.82
Ability to move around indoors	0 - 8	2.55 ± 2.10
Ability to move around for moderate distances (10-100ms)	0 - 8	2.33 ± 1.94
Ability to move around outdoors for more than 100ms	0 - 8	2.08 ± 1.92
Ability to go up and down stairs	0 - 3	0.46 ± 0.93
Ability to transfer from w/c into car	0 - 2	1.20 ± 0.82
Ability to transfer from the floor to the w/c	0 - 1	0.49 ± 0.50
Mobility Subscale Total	**0 - 40**	**16.46 ± 9.90**
SCIM Total Score	**10 - 100**	**57.22 ± 23.41**

4.4.4: Stratified analysis for functional abilities / independence

As seen below in Table 4.9, wheelchair users reported more limitations with functional abilities compared to walkers, indicating less independence and more reliance on assistance in order to complete tasks and functions compared to walkers. This was found for the self-care subscale (p<.001), respiratory and sphincter management subscale (p=.022), and the overall total scores (p<.001). See Table 4.9 below for subgroup analysis based on mobility status, i.e., wheelchair users versus functional walkers.

Table 4.9: Wheelchair users and walkers' functional abilities according to the SCIM

Subgroups	Wheelchair (mean)	Walker (mean)	T; p value
Self-care	14.05	19.36	**-2.686; (<.001)**
Respiratory and Sphincter Management	23.35	36.29	**-5.631; (.022)**
Mobility	12.77	32.79	-11.031; (.450)
Total SCIM	50.18	88.43	**-7.120; (<.001)**

p<.05

4.5. Objectively assessed PA volume and intensities

Nine percent (n= 7) of the participants did not adhere to the stipulated protocol i.e., did not wear the device for the prescribed time, leaving 91% of the participants (n= 69) who adhered to the prescribed wear time. For these participants, the total wear time documented for wheelchair users (n= 56) was 981.26 minutes/day and 974.25 minutes/day for walkers (n=13). The mean of the sum of the daily vector magnitudes (volume/step counts) for wheelchair users was 1209424.73/day and 679286.75 for walkers/day. Participants spent the majority of their time engaged in SED/ LIPA, with 98.3% reported for wheelchair users and 99.8% for walkers. Less time was spent in moderate and vigorous PA. It was further reported that wheelchair users spent 1.6% of time (15.36 minutes/day) engaged in moderate PA and 0.2% of time (1.6 minutes/day) engaged in vigorous PA, while walkers spent 0.2% of time (1.63 minutes/day)

engaged in moderate PA and 0.01% time (0.154 minutes/day) in vigorous PA. See Table 4.10 and figure 4.1 below for more details on the PA wear time, vector magnitude and PA intensities.

Table 4.10: Physical activity: Total wear time, vector magnitude and percentage of time spent in different intensities

Participants (n= 69)	total wear time (min)	vector magnitude	SED/LIPA	Moderate PA	Vigorous PA
wheelchair users (n=56)	981.26	1209424.73	98.3%	1.6%	0.2%
walkers (n=13)	974.25	679286.75	99.8%	0.2%	0.01%

*Total wear time: minutes/day, vector magnitude: volume/step counts

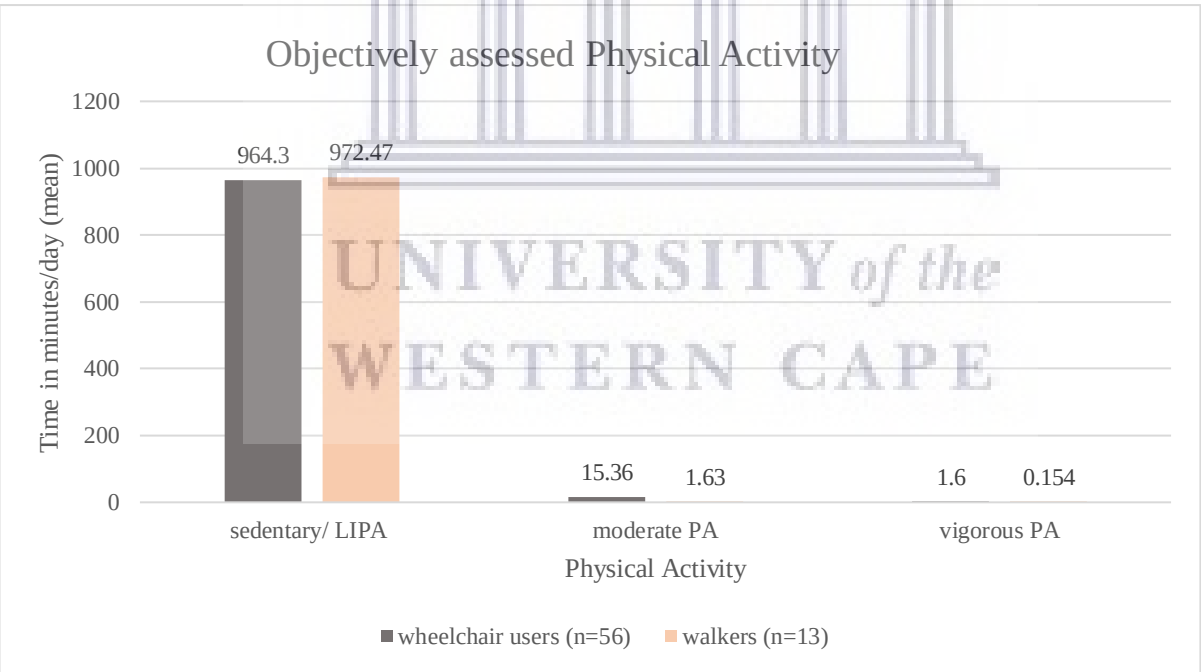

Figure 4.1 Objectively-assessed PA expressed as time spent in different intensities

4.5.1. Physical Activity: Gender

PA was further explored between males and females. Male wheelchair users (966.6 minutes/day) were slightly more engaged in SED/LIPA compared to male walkers (952.2 minutes/day), while female walkers (1083.9 minutes/ day) spent more time in SED/LIPA compared to female wheelchair users (946.8 minutes/day). Furthermore, female wheelchair

uses spent 2.5% of the time engaged in moderate PA and male walkers spent 0.2% of the time engaged in moderate PA. Only 0.1% time was engaged in vigorous PA by wheelchair users. See table 4.11 below for more details on PA intensities and gender.

Table 4.11: Gender and PA

PA intensities	wheelchair user (n= 49 male)	wheelchair user (n=7 female)	Walker (n=11 male)	walker (n=2 female)
Wear time (minutes/day)	982.2	972.6	954	1083.9
SED/LIPA				
minutes/day (mean)	966.6	946.8	952.2	1083.9
percentage wear time	98.4%	97.3%	99.8%	100%
Moderate PA				
minutes/day (mean)	13.8	24.6	1.8	0
percentage wear time	1.4%	2.5%	0.2%	0
Vigorous PA				
minutes/day (mean)	1.8	1.2	0	0
percentage wear time	0.1%	0.1%	0	0

4.5.2. Physical Activity: Time since Injury

It was noted that walkers in both age categories are spending an alarming time in SED/LIPA (99.9% and 99.8% respectively). Wheelchair users in both 1-2 years and 3-6 years since injury is spending 1.6% in moderate PA, and walkers in the 1-2 year injury group is spending 0.02% in moderate PA and 0.2% for the 3-6 year group. Walkers spent no time in vigorous PA while wheelchair users in 1-2 years spent 0.1% in vigorous PA and 0.2% for wheelchair users in the 3-6 year injury group. See table 4.12 below for more details on PA intensities and time since injury.

Table 4.12: Time since injury and PA

PA intensities	wheelchair user(1-2y)	wheelchair user (3-6y)	walker (1-2y)	walker (3-6y)
Wear time (min/day)	915	997.2	846.78	1012.2
SED/LIPA				
minutes/day (mean)	900	979.8	846.6	1010.4
percentage wear time	98.4%	98.8%	99.9%	99.8%
Moderate PA				
minutes/day (mean)	14.4	15.6	0.18	1.8
percentage wear time	1.6%	1.6%	0.02%	0.2%
Vigorous PA				
minutes/day (mean)	0.6	1.8	0	0
percentage wear time	0.1%	0.2%	0	0

4.5.3. Physical Activity: Age

It was further established that wheelchair users in the age category 46 years+ (34.8 minutes/day) were more engaged in moderate physical activity than younger participants (10.2 minutes/day), while younger wheelchair users were slightly more engaged in vigorous PA (0.2%) and 0.1% for those 46+ years. Walkers were predominantly spent most of their waking time in SED/LIPA with very minimal engagement in moderate PA (0.2%) and no engagement in vigorous PA. See table 4.13 below for more details on PA intensities and age.

Table 4.13: Age and PA

PA intensities	wheelchair user (18-45y)	wheelchair user (46+)	walker (18-45y)	walker (46+y)
Wear time (min/day)	979.8	986.4	940.8	1084.2
SED/LIPA				
minutes/day (mean)	967.8	950.4	939	1084.2
percentage wear time	98.8%	96.4%	99.8%	100%
Moderate PA				
minutes/day (mean)	10.2	34.8	1.8	0
percentage wear time	1.0%	3.5%	0.2%	0
Vigorous PA				
minutes/day (mean)	1.8	1.2	0	0
percentage wear time	0.2%	0.1%	0	0

4.5.4. Comparison of Physical activity behaviour (intensities) by various subgroups

Regarding gender, no significance was found between males and females in all PA intensities. Concerning years with SCI, a significant difference (p=.019) for vigorous PA between those living with SCI for 3 to 6 years and those living with the injury for 1 to 2 years were found. In addition, there were significant differences for moderate PA (p=.012) and vigorous PA (p=.008) levels between wheelchair users and walkers, with the former demonstrating higher levels of PA engagement. Lastly, a significant difference for moderate PA between older and younger groups (p<.001) was seen with the older group demonstrating greater levels of PA engagement of moderate intensity. No further significant differences in other intensity levels were noted for the various strata. See table 4.14 below which presents the comparisons of PA intensities across subgroup of the SCI population.

Table 4.14: Comparison of PA intensities across subgroup of the SCI population

Measures (n=69)	SED/LIPA (mean)	T; p value	Moderate (mean)	T; p value	Vigorous (mean)	T; p value
Gender: Male (n=60) Female (n=9)	964.13 977.26	-.221 (.873)	11.82 19.13	-.750 (.220)	1.36 1.13	.220 (.612)
Years with SCI: 1-2 years (n=14) 3-6 years (n=55)	888.40 985.55	-2.009 (.793)	11.43 13.11	-.205 (.987)	0.31 1.59	**-1.514** **(.019)**
Mobility status: wheelchair user (n=56) Walkers (n=13)	964.30 972.47	-.160 (.356)	15.36 1.63	**1.659 (.012)**	1.60 0.154	**1.681** **(.008)**
Age: 18-45 (n=54) 46-67 (n= 15)	962.68 977.21	-.299 (.773)	8.55 27.98	**-2.543** **(<.001)**	1.45 .79	.825 (.290)

p<.05; mean measurement: minutes

4.6 Summary

A total number of seventy-six participants were recruited to take part in this study, with a mean age of 36 years. The majority of the participants was male (88.2%) compared to females (11.8%). The main cause of the TSCI is due to assault (64.5%) with 50% classified as Asia A. A total of 98.6% of participants reported one or more secondary complication, with only one participant who reported no complications at the time of screening. The common secondary complications noted were muscle spasms (86.8%), joint or muscle pain (72.4%), bowel dysfunction (61.8%) and chronic pain (59.2%). Concerning functional independence, participants reported the most independence with the self-care subscale and the least independence reported for the mobility subscale. Furthermore, the objective measurement of PA indicated that participants are spending an alarming time in SED/LIPA with very minimal time in moderate and vigorous PA. Wheelchair users were also seen to be more active than walkers.

CHAPTER FIVE

DISCUSSION OF FINDINGS

5.1. Introduction

In this chapter the main findings of the study are presented and discussed in relation to the relevant literature on these aspects, and comparisons and differences highlighted. The sociodemographic and injury characteristics, secondary complications, functional independent indices and objectively assessed physical activity was presented and comparisons made to other local and international literature. The results of the study are linked to the components of the ICF, which is the theoretical framework of the study.

5.2. Sociodemographic and injury characteristics

In this study, from a total number of 76 participants, the majority of the participants were male with a median of 34. The primary cause of TSCI was due to assault, with a higher percentage for gunshot wounds. These findings of age and aetiology were similarly seen across local studies, which found assault to be the leading cause of TSCI followed by MVA and falls (Joseph and Nilsson Wikmar, 2016; Joseph et al., 2015). The traumatic nature of these SCI has resulted in severe injuries to the spine with more than 50% of participants classified as paraplegic with complete injuries. These were similarly discovered in other local studies as well which reported 50% of participants with paraplegia and 30% classified with complete injuries (Joseph and Nilsson Wikmar, 2016; Joseph et al., 2015). It is further noted within local research that TSCI is happening as a result of preventable causes such as interpersonal violence and MVAs, and commonly occurring in young males who are often the main breadwinners in the family. This causes financial hardship on families who often rely on the individual with SCI for basic necessities. In addition, PwSCI would generally require financial funding and access to healthcare services, home environment adjustments, vehicle adjustments or adaptive tools for basic needs after the injury (Bezuidenhout, Rhoda, Moulaee Conradsson, Theron & Joseph, 2022). These findings strongly indicate a need for preventative measures to be implemented to decrease the frequency of TSCI in developing countries (Rahimi- Movaghar et al., 2013).

These findings differ from more developed countries where the leading cause of TSCI has been found to be falls, violence and sport related injuries. Furthermore, it was noted that MVAs and falls are on the increase (DeVivo, Biering-Sørensen, New & Chen, 2011; Jackson, Dijkers, DeVivo & Poczatek, 2004). The mean age seen for MVAs were seen in those 45 years and younger, while the mean age for falls were seen in 45 years and over. Low height falls were common in the elderly, and often resulted in low trauma and incomplete injuries, which had faster recovery post injury. A similarity, however, seen in both developing and developed countries was gender, with the majority of the population being males. It is evident that the males are predominantly affected, and that the working force/breadwinners in the communities are largely affected. This could pose difficulties and place a burden on their families and children. This is evident in this current study that noted at the time of injury, 63.2% of participants indicated that they were employed while now post TSCI 82.9% has indicated that they are currently unemployed. It is also likely that severity of injury as well as a range of environmental factors could play a part in return to work and employment status.

5.3. Impairments: Secondary complications

The results of this current study revealed that more than 90% of participants experienced one or more secondary complication with only one participant reporting not experienced any secondary complications. These findings painted a dire situation as it differs from a local study done by Madasa, Boggenpoel, Phillips & Joseph (2020) that reported 69% of the participants reporting at least one complication, while 31% reported having none. Possible reasons for the vast difference seen in these similar local studies could relate to completeness of injury. In this current study, 50% of participants had complete injuries while the study by Madasa, Boggenpoel, Phillips & Joseph (2020), majority of participants (57%) had incomplete injuries,thus indicating that less secondary complications reported with those who have less severe injuries in terms of neurological fallout. This is further correlated within the current cohort, where a significant finding arose for injuries due to loss of sensation. We are able to further note that in both studies conducted in the South African context, completeness of injury has been identified as a factor to developing secondary complications. The common secondary complications reported across both local studies were muscle spasms and pain. Another factor to consider is the time period for this study, data collection commenced within the Covid-19 pandemic which resulted in a global public health crisis. During this period people opted to delay medical procedures or health care management due to the fear of contracting the Covid-

19 virus. The findings from local studies identified above indicate a need for health promotion strategies and active rehabilitation to address secondary complications such as pain and muscle spasms across the continuum of care.

5.4. Activity and Participation: Objectively assessed PA

To our knowledge, this is the first study to objectively measure PA in PwSCIs in South Africa. This study found an increase time spent in SED/LIPA, with both wheelchair users and walkers. The increase in SED/LIPA after SCI falls in line with previous studies, which also noted a decline in PA especially for wheelchair users. PwSCI and health care providers not educated or trained in SCI management may not understand the importance of and benefits of PA and may believe that resting or sleeping is necessary to conserve energy or decrease pain (Warms, Whitney & Belza, 2008). Generally ambulant PwSCI seem to be better at engaging in PA once they home, as they are able to stand and walk and partake in ADLs such as house chores, self-care, and perhaps able to move around their communities with less limitations than someone using a wheelchair (Warms, Whitney & Belza, 2008). These findings were evident in a longitudinal study done in Netherlands that followed a group of participants, from in-patient rehabilitation and into the community 1year post rehabilitation, and discovered that PA increased from 88.7± 36.1 min/day to 116± 59.2 min/day and sedentary behaviour decreased from 732.4± 81.9 min/day to 665± 121.3 min/day. These findings still however revealed an alarming time spent in SED/LIPA. The increase in PA was related to an increase in walking mobility within the community post discharge (Postma et al., 2020). Our study however contrasts this notion of walkers being more physically active (SED/LIPA: 99.8%). Various factors could influence the decrease in activity with ambulant participants in this current study, which we should take into consideration. Factors such as, safety and gang-related violence in communities (high incidence of assault with this cohort) impacting vulnerability, infrastructure and environmental challenges, walking speed, availability of an appropriate, or use of an, assistive device or attitudes of community members, are possibilities for poor PA and increased SED within the local context (Warms, Whitney & Belza, 2008). The findings in the study suggests the importance of more research on PA in walkers with SCIs to optimise health and participation, and incorporating rehabilitation interventions that allow and encourage the need for walkers to be independent and safe within the community.

The PA findings in this cohort corroborate with previous studies that report alarming time spent in SED/LIPA and poor engagement in moderate and vigorous PA (Eitivipart et al., 2021; Mat Rosly et al., 2018). The common findings seen across literature on measuring PA is that PwSCI are not meeting the recommended guidelines for PA to achieve beneficial outcomes. We can also conclude from these findings that this cohort does not meet recommended levels of PA. Understanding influencing conditions would be the first step to develop novel interventions and strategies to promote PA in future.

This study further explored variables such as gender, age and time since injury and their influence on PA intensities. As noted with gender, female participants revealed more time engaged in moderate PA than males. The sample size however for females in this study is limited, so this finding did not yield statistical significance. This finding could be attributed to the fact that women are more likely to engage in household tasks and family activities as opposed to their male counterparts. (Warms, Whitney & Belza, 2008). These findings were similarly seen in two other studies that reported no significant differences in gender (Nooijen et al., 2015; Warms, Whitney & Belza, 2008). A common thread however noted in all studies is small sample sizes with limited female participants.

Furthermore, we saw that wheelchair participants living with their injuries for a longer time spent more time engaged in vigorous PA than those with acute injuries, while those in the older age category was more engaged in moderate PA compared to those younger. The results of this study may provide a hopeful possibility that wheelchair users are finding ways to be more active within their home and community environments and including PA into their daily routines. Furthermore, wheelchair users depending on severity of the injury, require more effort, EE and physical exertion to complete ADLs, giving the impression of engagement in moderate or vigorous PA. Similarly, older participants might require more effort to complete tasks than younger participants. As seen in other literature, similar findings were noted with those living with their injuries for a longer time showing more engagement in PA than those with recent injuries (Postma et al., 2020). Additionally, other studies found that younger individuals are more active than older individuals (Postma et al., 2020; Warms, Whitney & Belza, 2008).

5.5. Functional abilities: Spinal cord independence measure self-report

The results of this study indicated more independence within the self-care subscale, average independence within the respiratory and sphincter management subscale and the least independence presented for mobility subscale. These results clearly indicate that the participants in this cohort displayed more independence with basic upper limb tasks but however battled with more complex tasks that required more components to execute and that required more exertion and EE. For the self-care subscale, more independence was seen for dressing and undressing the upper body and with eating and drinking. Participants in this study were injuries C6 and below with 50% classified as complete/ incomplete injuries which means they had upper limb function and the ability to participate with upper limb functional tasks while difficulty with lower limb activities would be evident as well. With the respiratory and sphincter management subscale, poor independence with toilet function was evident. This complex task involves many components such as independence with toilet use, dressing and undressing lower limb clothes and clearing the buttocks in order to clean themselves. The mean scores reported was 2.84± 2.18 for toilet function. A multicentre observational study done in Germany reported similar findings with more independence reported for the self-care and respiratory and sphincter management subscale and poor independence with mobility function (18.64 mean) (Möller et al, 2021). Our findings are consistent with previous studies, which highlights these challenges in particular with bladder and bowel dysfunction, which over time has indicated deterioration due to incontinency and constipation.

Concerning mobility, this cohort reported the most independence with bed mobility and movement indoors. Participants indicated the most difficulty experienced within the mobility subscale indicating wide variety of difficulty with functions including lower limb involvement. A cross-sectional study based in Finland similarly reported poor functional abilities with mobility with the least independence displayed while self-care yielded the most independence (Majamäki et al., 2022). Factors such as severity of injury (ASIA A with more limitations), time since injury (acute injuries with lower functional independence) and age (older participants tend to have lower scores) could all impact functional independence with tasks of daily living (Majamäki et al., 2022). As we have seen in research factors such as age, severity of injury and time since injury has shown to significantly influence PwSCIs independency and function which can be seen in these findings with the lowest scores in the mobility domain (wheelchair propulsion, walking with or without aid, transfers) (Majamäki et al., 2022). Based

on the results of this study it was also found that persons with complete injuries experience more difficulties and limitations than those with incomplete injuries.

5.6. Summary

In this chapter, the researcher reviewed the main findings of this current study. The literature was reviewed and comparisons made to the findings, with specific mention to secondary complications, functional abilities, and physical activity. This studies finding aligned with previous studies showing that males are more predominantly affected, mostly due to assault. Overall we noted participants experiencing a range of different secondary complications and participants reporting more independence with upper limb functional tasks. We further found that regardless of mobility status (wheelchair user or walker), participants were mostly engaged in SED/LIPA. Furthermore, the results revealed wheelchair users are more engaged in moderate and vigorous PA compared to walkers, and that older participants were more significantly engaged in moderate PA compared to the younger participants. These findings could indicate that wheelchair users are findings ways to be more active.

CHAPTER SIX

CONCLUSION, RECOMMENDATIONS AND LIMITATIONS

6.1. Conclusion

In relation to objective one, it was determined that males were more susceptible to sustain TSCIs (88.2%) due to interpersonal violence such as assault (64.5%) with gunshot wounds being the leading cause (46.1%). With males being predominantly affected, the breadwinners in the families are impacted, since men are more likely to be the breadwinners.

Concerning objective two, to determine the prevalence of secondary complications and functional independence of community- dwelling participants. It was observed that more than 80% of participants reported three or more complications which could imply that specialised services should be made available to manage it and that educational programmes be implemented to educate patients and family members about the risk factors involved when developing secondary complications. Regarding functional independence, limitations were seen in bathing and dressing the lower body. With respiratory and sphincter management, difficulties were mostly reported for bladder management and the ability to use the toilet. Furthermore, with mobility, participants mostly experienced difficulty with transfers to and from the floor as well as mobilising indoors and outdoors.

Pertaining to objective three, this study revealed an alarming amount of time spent in SED/LIPA. It is evident that this cohort group was not meeting the recommended WHO guidelines for PA benefits.

With objective four, the study further revealed that PwSCIs living with an injury for a long time are more engaged in vigorous PA than those with recent injuries. In addition, wheelchair users were more engaged in moderate PA and vigorous PA compared to walkers. These findings could indicate that wheelchair users are either finding ways to be more physically active or that wheelchair users are having to exert themselves more with tasks compared to walkers. It is likely that wheelchair users have more appropriate assistive devices to meet their needs as opposed to walkers. This does point to the need to further investigate PA with walkers. Furthermore, this study revealed a significant finding for the older age group being more engaged in moderate PA compared to younger participants. Previous literature has shown that

younger PwSCIs are generally more active than those who are older, which was similarly discovered in this study as well, except for moderate PA.

6.2. Recommendations

- Majority of participants are leading sedentary lifestyles. Thus, active rehabilitation should focus on physical exercise techniques to improve PA levels in individuals with TSCIs, especially walkers but wheelchair users as well, in the Cape Metropole region in South Africa.
- As part of the rehabilitation program, educational strategies should promote the functional independence to improve mobility in terms of transfers and manipulating terrain.
- Since most of the participants experienced at least one secondary medical complication, a need exists to provide education and self-management interventions to prevent its occurrence. Further research is required to assess the relationship between the nature and number of complication and physical activity behaviour.
- In an attempt to reduce the prevalence of secondary complications, yearly follow-ups to monitor patient's progress and identification of any secondary complications should be implemented to assess the risk of cardiovascular disease, functioning decline, and early detection of preventative complications.
- TSCIs commonly affect males in the prime of their lives and subsequently unemployment follows. A need exists to equip TSCIs with skills to enable gainful employment.
- Subsequently, longitudinal studies should be conducted to ascertain the direction of the relationship between exposures and outcomes, such as PA, and could be conducted at different time intervals to determine how these variables evolve over time.

6.3. Limitations

One of the major challenges in this community based study was the recruitment of participants. The SCI registries were outdated and did not reflect the participants contact details accurately as a result researches resorted to driving into the communities in an attempt to locate the participants. Many participants lived in high-violence and unsafe areas, making driving into

the communities challenging and stressful due to safety concerns. This accounts for the sample size of the study.

Due to device constraints all individuals were fitted with one Actigraph wGT3X-BT accelerometer only. There could be a possibility that upper limb specific ADLs may not have been detected in participants who were wearing ankle monitors and the same could be said for the reverse. Future studies should assess the attachment of two devices per participant for the study period. Furthermore, the addition of a subjective PA tool coupled with an objective device could add valuable information about PA behaviour.

There are no SCI specific cut-points for ankle worn activity monitors available. The most appropriate cut-points were retrieved from previous literature but were specific to older aged able-bodied individuals. A need exist to determine the energy expenditure of walkers with SCI to derive calibrated cut-points specific to the population.

Methodologically, this was a cross-sectional study and the direction of relationship between exposures and outcomes is not known and should be studied in future longitudinal studies to better understand the influences on PA. Furthermore, although the sample size was optimal in relation to other international studies, it was not large enough to develop a multivariable model to ascertain independently associated factors of PA volume and intensities. Future studies should include a larger sample to study several factors.

Lastly, we do not know the extent to which the environment interacted with PA behaviour. Since PA occurs in a natural context, an assessment of the environment should be taken into account in future.

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APPENDICES

Appendix 1: Ethics clearance letter

UNIVERSITY of the WESTERN CAPE

Department of Institutional Advancement
University of the Western Cape
Robert Sobukwe Road
Bellville 7535
Republic of South Africa

60 YEARS of hope, action & knowledge

2 November 2021

Ms A Gabriels
Physiotherapy
Faculty of Community and Health Sciences

Ethics Reference Number BM19/7/2

Project Title: Physical activity behavior of community dwelling persons with traumatic spinal cord injury in Cape Town, South Africa

Approval Period: **22 October 2021 – 22 October 2024**

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project and the requested amendment to the project.

Any further amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report annually by 30 November for the duration of the project.

For permission to conduct research using student and/or staff data or to distribute research surveys/questionnaires please apply via:
https://sites.google.com/uwc.ac.za/permissionresearch/hom

The permission letter must then be submitted to BMREC for record keeping purposes.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

NHREC Registration Number: BMREC-130416-050

FROM HOPE TO ACTION THROUGH KNOWLEDGE.

Appendix 2: English Information Sheet

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542 Fax: 27 21-959 1217

E-mail: aeyshagabriels@gmail.com

INFORMATION SHEET

Project Title: Physical Activity Behaviour of community dwelling persons with traumatic spinal cord injury in Cape Town, South Africa

What is this study about?

This is a research project being conducted by Aeysha Gabriels at the University of the Western Cape. We are inviting you to participate in this research project because you have sustained a traumatic spinal cord injury. The purpose of this research project is to determine the Physical Activity behaviour (volume and intensity) as well as the association between physical activity and secondary complications, and physical activity of community participation of SCI population in Cape Town. This information can help improve the health care received by spinal cord injury individuals so that they can live better.

What will I be asked to do if I agree to participate?

After signing a consent form, you will be asked to complete a form with several questions. This will be done at your home in the community where you live. You will be contacted to arrange a convenient time and place to meet. The questions you will be asked include questions about your injury, how you are managing with activities you have to perform, and how you view your general health. This will take approximately one hour to complete, and researchers will assist you as best they can. You will also be asked to wear a small device, which looks like a watch, on your wrist. Researchers will put the device on for you, and you will have to wear it for 7 days. You are allowed to take it off only when bathing. This device will measure your movement. After 7 days, you will be contacted by the researchers and the device will be collected. The device will not affect you in any way, and you can continue doing your normal activities.

Would my participation in this study be kept confidential?

The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity, the surveys will not contain information that may personally identify you. All the data will be stored in password protected files on a computer. Identification codes of personal details will be displayed on data forms. Your name will not be included on the surveys and the other collected data. A code will be placed on surveys and other collected data. Through the use of an identification code, the researcher will be able to link your survey to your identity. Only the researcher will have access to the identification key. If we write a report or an article about this research project, your identity will be protected.

What are the risks of this research?

There may be some risks from participating in this research study. All human interactions and talking about yourself or others carry some amount of risk. However, we will minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about the different health care pathways followed by persons with a traumatic spinal cord injury. We hope that, in the future, other people might benefit from this study through improved understanding of appropriate health care for persons with a traumatic spinal cord injury.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

What if I have questions?

This research is being conducted by Aeysha Gabriels from the Physiotherapy Department at the University of the Western Cape. If you have any questions about the research study itself, please contact:

Principle investigator: Aeysha Gabriels
Contact number: 0646879777
Email address: aeyshagabriels@gmail.com

Or

Dr. Conran Joseph
University of the Western Cape
Email: Conran.Joseph@gmail.com

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof Michael Rouwe
Head of Physiotherapy department
University of the Western Cape
Private Bag X17
Bellville 7535
Mrouwe@uwc.ac.za.

Or

Prof Anthea Rhoda
Dean of the Faculty of Community and Health Sciences
University of the Western Cape
Private Bag X17
Bellville 7535
Chs-deansoffice@uwc.ac.za.

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

Biomedical Research Ethics Committee
University of the Western Cape
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Appendix 3: Afrikaans information sheet

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INFORMASIEVORM

Titel van die navorsingsprojek: Physical Activity Behaviour of community dwelling persons with traumatic spinal cord injury in Cape Town, South Africa

Waaroor gaan die studie?

Dit is 'n navorsingsprojek wat gelei word deur Aeysha Gabriels by die Universiteit van die Wes-Kaap. Ons nooi u om deel te neem aan die studie, want u is 'n persoon wat 'n traumatise spinale koord besering gehad het. Die doel van hierdie navorsingsprojek is om die fisiese aktiwiteitsgedrag (volume en intensiteit) asook die verband tussen fisiese aktiwiteit en sekondêre komplikasies van SCI-bevolking in Kaapstad te bepaal. Ons wil ook die verband tussen fisiese aktiwiteitsgedrag en gemeenskapsdeelname sien. Die informasie kan help om die gesondheidsorg vir individue met spinale koord beserings te vebeter sodat hulle 'n beter lewe kan voer.

Wat sal van my verwag word as ek besluit om aan die studie deel te neem?

Eerstens sal u gevra word om 'n skriftelike toestemmingsvorm te onderteken. As u nie in staat is om die vorm te teken, as gevolg van u besering,nie, sal u gevra word om mondelinge toestemming te gee, wat deur die navorser met 'n klankopnametoestel opgeneem sal word. As u toestemming gegee het, sal u gevra word om 'n vorm met veskeie vrae te beantwoord. Dit sal in die gemeenskap waar u bly voltooi word. Die navorser sal u kontak om 'n afspraak te maak wat op 'n gerieflike tyd en plek vir u sal plaasvind. Die vrae het betrekking op u besering, hoe u daaglikse aktiwiteite ervaar en u siening van u algehele gesondehied. Dit sal ongeveer 'n uur neem om die vraelys te voltooi en die navorser sal u help tot die beste van hul vermoë, indien nodig. U sal ook gevra word om 'n klein apparaat, wat soos 'n

horlosie lyk, op u arm of heup te dra. Die apparaat word gebruik om beweging te meet. Die navorsers sal die apparaat vir u aansit en u sal gevra word om dit vir 7 dae te dra en slegs af te haal wanneer u stort of bad, en slaap. Na 7 dae sal die navorser u weer kontak om die apparaat te kom afhaal. Die apparaat sal u op geen manier negatief affekteer nie en u sal in staat wees om met u normale aktiwiteite voort te gaan.

Sal my deelname aan die studie vertroulik hanteer word?

Die navorsers onderneem om u identiteit en deelname aan die studie te beskerm. Om u anonimiteit te verseker, sal die opnames geen inligting bevat wat u kan identifiseer nie. Dit het ook betrekking tot die klankopnames wat slegs toeganklik sal wees vir die navorsers. Alle data sal gestoor word op rekenaars wat met 'n wagwoord beskerm word. Identifikasiekodes van persoonlike inligting sal op die datavorms verskyn. U naam sal nie op die vraelys en ander ingesamelde data verskyn nie. Slegs 'n kode sal daarop verkyn. Die navorser sal dus u data kan identifiseer deur gebruik te maak van 'n identifikasiekode. Slegs die navorser sal toegang hê tot die identifikasiesleutel. As ons 'n verslag of artikel oor die navorsingsprojek skryf, sal u identiteit beskerm word.

Wat is die risikos van hierdie navorsing?

Daar is 'n mate van risiko om aan die studie deel te neem. Alle menslike interaksies en om oor uself of ander mense te praat dra 'n mate van risiko. Ons sal die risikos tot die beste van ons vermoë verlaag en sal dadelik reageer om te help as u enige ongerief, sielkundig of anders, ervaar tydens u deelname aan die studie. Waar nodig sal 'n toepaslike verwysing na 'n geskikte professionele persoon vir verdere hulp of intervensie gemaak word.

Wat is die voordele van hierdie navorsing?

Die navorsing is nie ontwerp om u persoonlik te bevoordeel nie, maar die resultate kan die navorser in staat stel om meer te vestaan oor die versillende gesondheidsorgopsies wat mense met traumatise spinale koord beserings kan volg. Ons hoop vir die toekoms is dat ander mense, deur die studie, gehelp kan word deur 'n beter begrip van toepaslike gesondheidsorg vir mense met traumatise spinale koord beserings te vekry.

Is dit nodig vir my om deel te wees van die studie, en kan ek my deelname staak op enige tyd?

Deelname aan die studie is heeltemal vrywillig. U kan kies om nie aan die studie deel te neem nie. As u besluit om deel te neem, kan u enige tyd besluit om te staak. As u besluit om nie deel te neem nie of enige tyd besluit om op te hou, sal dit geen negatiewe gevolge het of tot 'n verlies van voordele lei waarvoor u mag kwalifiseer nie.

Wat doen ek as ek enige vrae het?

Die studie word gelei deur Aeysha Gabriels van die Fisioterapie Departement by die Universiteit van die Wes-Kaap. As u enige vrae oor die navorsing het, kontak asseblief die volgende persoon:

Hoofnavorser: Aeysha Gabriels

Kontaknommer: 0646879777

E-pos addres: aeyshagabriels@gmail.com

Of

Dr. Conran Joseph

Universiteit van die Wes-Kaap

E-pos: cjoseph@uwc.ac.za

Indien u enige vrae het oor die studie of oor u regte as novorsingsdeelnemer, of indien u enige probleme ondervind het met betrekking tot die studie en dit wil aanmeld, kontak asseblief die volgende persoon:

Prof Michael Rowe

Hoof van die Fisioterapie Departement

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Of

Prof Anthea Rhoda

Dekaan van die Fakulteit Gemeenskap en Gesondheidswetenskappe

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chs-deansoffice@uwc.ac.za.

Hierdie navorsing is goedgekeur deur die Universiteit van Wes-Kaapland se Biomediese Navorsingsetiekkomitee.

Biomediese Navorsingsetiekkomitee

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Appendix 4: Xhosa information sheet

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LINKCUKACHA ENGCACISO

ITayitile yeProjekthi: Physical Activity Behaviour of community dwelling persons with traumatic spinal cord injury in Cape Town, South Africa

Isifundo simalunga nantoni?

Le Prokethi yoPhando iqhutywa ngu Aeysha Gabriels kwi Dyunivesithi yase Ntshona koloni. Siyakumema ukuba ube yinxaxheba yoluphando ngoba nawe uye wafumana ukulimala kwentamo yomgudu. Injongo yale projekthi yophando kukuqinisekisa indlela yokuziphatha yomzimba (umthamo nokuqina) kunye nombutho phakathi kokusebenza ngokomzimba kunye neengxaki zesibini ze-SCI kubemi baseKapa. Phanda ubudlelwane phakathi kokuziqhelanisa nomsebenzi wentatho-nxaxheba yoluntu. Olu lwazi lunokunceda ukuphucula ukhathalelo lwezempilo olufunyanwa ngabantu abalimele kwintamo yomgudu.

Ndizakubuzwa ntoni na ukuba ndivuma ukuthatha inxaxheba?

Okokuqla, uzakucelwa ukuba utyikitye I fomu yemvume. Ukuba awukwazi ukutyikitya I fomu ngenxa yemiphumela yokulimala kwakufuneka usinike imvume ngomlomo yona ke iyakufumaneka ngokuthi umpandi asebenzise I –audio rekhodi. Emva kokunika imvume uzakucelwa ugcwalise ifomu ememibuzo eliqela. Oku kuya kugqitywa ekhayeni lakho kwindawo ohlala kuyo. Sizakuqhagamshelana nawe ukulungisiselela ixesha elifanelekileyo nendawo yokudibanela. Imibuzo ozakuyibuzwa ibandakanya imibuzo ngokulimala kwakho, nokuba uzilawula njani emisebenzini oyenzayo, nendlela ojongana nempilo yakho jikelele. Yonke lento iyakuthatha iyure enye ngokuqikelela, kwaye abaphandi bakuncedisana nawengakho konke abanako. Uyakucelwa nxibe isixhobo esincinci esibukeka njenge wotshi esihlahleni okanye ethangeni/amadywantsi. Abaphandi bazakunxibisa esi sixhobo

kangangentsuku ezisixhenxe. Uvumelekile usikhulule xa uhlamba qha. Esisingxobo sizakubala imigama othi uyihambe. Emva kwentsuku ezisixhenxe abaphandi bazakuqhagamshelana nawe kwaye nesixhobo esincinci sizakuthathwa. Esisixhobo asizokuphazamisa nawe kwaye uzakukwazi ukuqhubeka nemisebenzi yakho njengesiqhelo.

Ingaba ukuthatha kwam inxaxheba koluhlelo okanye phando kuzogcineka kuyimfihlelo?

Kuluxanduva lwabaphandi beliphepha ukukhusela ubuni kwakunye nobume begalelo lakho. Ukuqinisekisa ukhuselo lobuni bakho, abaphandi bazokugcina incukacha ezingakutyhila njengomnombo wabo zikhuselekile. Oku kuquka ushicelelo lukanomathotholo kwakunye nemifanekiso yekhamera, izokuba ngabaphandi kuphela abanemvume yokuwafumana lamashicelelo. Yonke ingcazelo izokugcinwa kwimiqulu ekhuselwe ngamanani kwiKhompyutyha. Yonke I datha iyakugcinwa kwifiyile ezikhuselweyo zephasiwedi kwi khompyutha. Ikhowudi yokuchonga yeencukchs ezizodwa iyakuboniswa kwi fomu yedatha. Igama lakho alizukufakwa ku phando noqokelelo lwe datha. Ikhowudi izakubekwa kuohando naku qokelelo lophando. Ngokusebenzisa ukusebenzisa ikhowudi yokuchonga, abaphandi bazakukwazi ukuqhagamshela uphando kwisazisi. Iyakubangabaphandi kuphela abanemvume kwisithixo sesazisi. Ukuba sibhala Ingxelo okanye inqaku ngoluphado lwe projekthi, isasizo sakho siyakukhuselwa

Zeziphi ingcipheko zoluphando?

Lungakho ungcipheko ngokuthatha inxaxheba koluphando. Lonke unxulumelwano lwabantu nokuthetha ngawe okanye ngabanye abantu luthwala ungcipheko oluthile. Kodwa ke, sizolunciphisa kangangoko ungcipheko olunjalo kwaye senze njalo ngokungxamiseka khonukuze sincedisane nawe ukuba ugilana nokungoneliseki kwengqondo okanye nangaluphi na uhlobo. Apho kufuneka khona, umntu angadluliselwa kumongi osemthethweni nothevetshe khona ukuze amjonge ngcono okanye banzi.

Zezipho inzuzo zoluphando?

Oluphando alwenzelwanga ukunceda wena siqu, kodwa iziphumo zalo zingakunceda uphande okanye ufunde banzi ngamacandelo ezempilo ahlukeneyo alandelwa okanye enziwa ngabantu abahlukunyezwe kukulimala komqolo. Siyathemba uba ekuhambeni kwexesha nabanye abantu bangaxhamla kolufundo okanye uphando ngokusebenzisa ukuqond okuphuculiweyo kwenkathalo enempilo yomntu onomonakalo wentamo yomgudu.

Kunyanzelekile ndithathe inxaxheba koluphando, kwaye ndingakwazi ukuyeka nanini na?

Ukuthatha inxaxheba koluphando ngokuzithandela ngokupheleleyo. Onokukhetha ukungathathi nxaxheba kukho konke. Ukuba ugqiba ukuthatha inxaxheba koluphando, ungayeka ukuthatha inxaxheba nanini na, awuyi kuhlawula okanye ulahlekelwe yinzuzo apho ufaneleka khona.

Ndenza njani ukuba ndinembuzo?

Oluphando luqhutywa nguAeysha Gabriels osuka kwicandelo lokulolonga umzimba iPhysiotheraphy kwiDyunivesithi yaseNtshona Koloni. Ukuba unemibizo ethe vetshe malunga noluphando, ungaqhangamshelana naye.

Umpandi womgaqo: Aeysha Gabriels

Umxeba: 0646879777

Idilesi yemeyile: aeyshagabriels@gmail.com

Okanye

Gqirha. Conran Joseph

I-Dyunivesithi yase Ntshona Koloni

Idilesi yemeyile: cjoseph@uwc.ac.za

Ukuba ngaba nayo nayiphi na imibuzo malunga nesisifundo kunye namalunglo akho njengo mcedisi wophando okanye unqwenela ukubika iingxaki odibene nazo malunga nesisifundo, ungaqhagamshelana no:

Prof Michael Rowe

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Okanye

Prof Anthea Rhoda

Dini kwicandelo loluntu kunye nesayensi yezempilo

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Okanye

Biomedical Research Ethics Committee

University of the Western Cape

Private Bag X17

Bellville

7535

Tel: 021 959 4111

E-mail: research-ethics@uwc.ac.za

Oluphando lupasiswe sisigqeba sekomiti yophando IYunivesithi yaseNtshona Koloni kunye nekomiti yezemigomo Biomedical.

Appendix 5: Consent form English

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542, Fax: 27 21-959 1217
E-mail: aeyshagabriels@gmail.com

CONSENT FORM

Title of Research Project: ***Physical activity behaviour of community dwelling persons with traumatic spinal cord injury in Cape Town, South Africa***

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits. I am willing to accept being audio recorded if I cannot provide written consent.

___ I agree to be **[**videotaped/audiotaped/photographed**]** during my participation in this study.
___ I do not agree to be **[**videotaped/audiotaped/photographed**]** during my participation in this study.

Participant's name……..

Participant's signature…….

Witness…….

Date……

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Bellville
7535
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E-mail: research-ethics@uwc.ac.za

Appendix 6: Consent Form Afrikaans

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542, Fax: 27 21-959 1217
E-mail: aeyshagabriels@gmail.com

TOESTEMMINGSVORM

Titel van die navorsingsprojek: ***Physical activity behaviour of community dwelling persons with traumatic spinal cord injury in Cape Town, South Africa***

Die studie is aan my verduidelik in 'n taal wat ek verstaan. My vrae oor die studie is beantwoord. Ek verstaan wat my deelname sal betrek en ek stem in om deel te neem uit eie keuse en vrye wil. Ek verstaan dat my identiteit nie bekend gemaak sal word nie. Ek verstaan dat ek enige tyd van die studie kan onttrek sonder om 'n rede te verskaf en dat dit geen negatiewe gevolge of 'n verlies van voordele sal inhou nie. Ek is bereid om te aanvaar dat ek klank opgeneem word as ek nie skriftelike toestemming kan gee nie.

____Ek stem in **[**video-opname/klankopname/gefotografeer**]** tydens my deelname aan hierdie studie.
____Ek stem nie saam **[**video-opname/klankopname/gefotografeer**]** tydens my deelname aan hierdie studie.

Deelnemer se naam……..

Deelnemer se handtekening……

Getuie……

Datum……

Biomedical Research Ethics Committee
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Private Bag X17
Bellville
7535
Tel: 021 959 4111
E-mail: research-ethics@uwc.ac.za

Appendix 7: Consent form Xhosa

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542, Fax: 27 21-959 1217
E-mail: aeyshagabriels@gmail.com

IFOMU YOKUVUMA

Isihloko seProjekthi yophano: ***Physical activity behaviour of community dwelling persons with traumatic spinal cord injury in Cape Town, South Africa***

Isifundo sicacisiwe kum ngoLwimi endiluvayo. Imibuzo yam ngesisifundo iphenduliwe.Ndiyayiqonda inxaxheba yoku zibandakanya kwam, futhi ndiyavuma ukuthatha inxaxheba ngentando yam noku khethwe ndim okanye okufunwa ndim. Ndiyayiqonda into yokuba incukacha zam azizokwaziswa nabanina. Ndiyayiqonda into yokuba ndingakwazi ukuzikhupha okanye ukurhoxa kwesisifundo naninina ngaphandle kokunikezela izizathu nangaphandle kokoyika iziphumo ezibi okanye ukuphulukana nenzuzo. Ndizimisele ukwamkela ukurekhodwa ngeaudiyo ukuba andikwazi ukunika imvume ebhaliweyo.

_____ Ndiyavuma ukuba [videotaped / audiotaped / photographed] ngexesha lokuthatha inxaxheba kweso sifundo
_____ Andivumelani ukuba [videotaped / audiotaped / photographed] ngexesha lokuthatha inxaxheba kweso sifundo.

Igama lomncedisi wophando…….

Utyikityo lomncedisi wophando…….

I-Deyiti……

Ubungqina.....

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Appendix 8: Conceptual Framework

		ICF			
Instrument	Data element	CF	BS & BF	Activity	Participation
	Birth date	x			
	Injury date	x			
	Gender	x			
	Acute admission	x			
	Final inpatient discharge	x			
International	Days hospitalized	x			
SCI	Injury aetiology	x			
Core Data Set	Vertebral injury		x		
	Associated injury		x		
	Spinal surgery	x			
	Ventilator assistance		x		
	Neurological		x		
	Classification				
Self-made	current residence	x			
Questionnaire	employment status at time	x			
	Of injury				
	Current employment status	x			
	Marital status	x			
	Highest educational status	x			
Secondary	16 items		x	x	x
Health					
Complication					
Scale					
SCIM SR	17 items		x	x	x
Accelerometer	PA volume and intensity			x	x

CF= Contextual factors; BS= Body structure; BF= Body function; SCIM SR= Spinal Cord Independence Measure self-report; Accelerometer= Agtigraph Wgt3X-BT

Appendix 9: International spinal cord injury core data set

INTERNATIONAL SPINAL CORD INJURY CORE DATA SET (VERSION 2.0)—DATA COLLECTION FORM

Dates (YYYYMMDD)

Birth date: __ __ __ __/__ __/__ __
Injury date: __ __ __ __/__ __/__ __
Acute admission: __ __ __ __/__ __/__ __
Rehabilitation admission: __ __ __ __/__ __/__ __
Final Inpatient discharge __ __ __ __/__ __/__ __
Date of death: __ __ __ __/__ __/__ __

Gender: ▫ Male ▫ Female ▫ Transgender and other related ▫ Unknown

Injury etiology:
▫ Sports;
▫ Assault;
▫ Transport;
▫ Fall;
▫ Birth injury or other traumatic cause, Specify:_____;
▫ Congenital or genetic etiology (for example, spina bifida);
▫ Degenerative non-traumatic etiology;
▫ Tumor—benign;
▫ Tumor—malignant;
▫ Vascular etiology (for example, ischemia, hemorrhage, arteriovenous malformation);
▫ Infection (for example, bacterial, viral);
▫ Other non-traumatic spinal cord dysfunction, Specify:_____;
▫ Unspecified or Unknown

Vertebral injury: ▫ No ▫ Yes ▫ Unknown

Associated injury: ▫ No ▫ Yes ▫ Unknown

Spinal surgery: ▫ No ▫ Yes ▫ Unknown

Ventilatory assistance:
▫ No;
▫ Yes, <24 h per day at discharge;
▫ Yes, 24 h per day at discharge;
▫ Yes, unknown number of hours per day at discharge;
▫ Continuous positive airway pressure (CPAP) for sleep apnea;
▫ Unknown

Place upon discharge/current residence:
▫ Private residence: includes house, condominium, mobile home, apartment or houseboat;
▫ Hospital: includes mental hospital or other acute care hospital for management of continuing medical issues after spinal cord injury-related care and/or rehabilitation is completed;
▫ Nursing home: includes skilled nursing facilities and institutions providing essentially long-term, custodial, chronic disease care;
▫ Assisted living residence: includes residential non-institutional locations in which some level of support for activities of daily living is provided;
▫ Group living situation: includes transitional living facility or any residence shared by non-family members;
▫ Correctional institution: includes prison, penitentiary, jail, correctional center and so on;
▫ Hotel or motel;
▫ Homeless: includes cave, car, tent and so on;
▫ Deceased;
▫ Other, unclassified;
▫ Unknown

Neurological Data

Acute admission
Date of examination
__ __ __ __/ __ __/ __ __
Sensory level
Left Right
__ __ __ __ __ __
Motor level
Left Right
__ __ __ __ __ __
ASIA Impairment Scale
__

Final inpatient discharge
Date of examination
__ __ __ __ /__ __/ __ __
Sensory level
Left Right
__ __ __ __ __ __
Motor level
Left Right
__ __ __ __ __ __
ASIA Impairment Scale
__

Self-made Questionnaire:

1. Current residence

2. Employment status at time of injury

3. Current employment status

4. Marital status

5. Highest educational level obtained

Appendix 10: Secondary complications

The Spinal Cord Injury Secondary Conditions Scale

Health Problem	Description	Rating
Pressure sore(s)	These develop as a skin rash or redness and progress to an infected sore. Also called skin ulcers, bedsores, and decubitus ulcers.	0 1 2 3
Injury caused by loss of sensation	Injury may occur because of a lack of sensation, such as burns from carrying hot liquids in the lap or sitting too close to a heater or fire.	0 1 2 3
Muscle spasms (spasticity)	Spasticity refers to uncontrolled, jerky muscle movements, such as uncontrolled muscle twitch or spasm. Often spasticity increases with infection or some kind of restriction, like a tight shoe or belt.	0 1 2 3
Contractures	A contracture is a limitation in range of motion caused by a shortening of the soft tissue around a joint, such as an elbow or hip. This occurs when a joint cannot move frequently enough through its range of motion. Pain often accompanies this problem.	0 1 2 3
Heterotopic bone ossification	This is an overgrowth of bone, often occurring after a fracture. Early signs include a loss of range of motion, local swelling and warmth at the area to the touch. This condition must be diagnosed by a physician.	0 1 2 3
Diabetes mellitus	Diabetes is a problem resulting from irregularities in blood sugar levels. Symptoms include frequent urination and excessive thirst. This condition is diagnosed by a physician.	0 1 2 3
Bladder dysfunction	Incontinence, bladder or kidney stones, kidney problems, urine leakage and urine back up are all symptoms of bladder dysfunction. NOTE: There is a separate item for urinary tract infections.	0 1 2 3
Bowel dysfunction	Diarrhea, constipation, ''accidents,'' and associated problems are signs of bowel dysfunction.	0 1 2 3
Urinary tract infections	This includes infections such as cystitis and pseudomonas. Symptoms include pain when urinating, a burning sensation throughout the body, blood in the urine and cloudy urine.	0 1 2 3
Sexual dysfunction	This includes dissatisfaction with sexual functioning. Causes for dissatisfaction can be decreased sensation, changes in body image, difficulty in movement, and problems with bowel or bladder, like infections.	0 1 2 3
Autonomic dysreflexia	Autonomic dysreflexia, sometimes called hyperreflexia, results from interference in the body's temperature regulating systems. Symptoms of dysreflexia include sudden rises in blood pressure and sweating, skin blotches, goose bumps, pupil dilation and headache. It can also occur as the body's response to pain where an individual doesn't experience sensation.	0 1 2 3
Postural hypotension	This involves a strong sensation of lightheadedness following a change in position. It is caused by a sudden drop in blood pressure.	0 1 2 3
Circulatory problems	Circulatory problems involve the swelling of veins, feet or the occurrence of blood clots.	0 1 2 3
Respiratory problems	Symptoms of respiratory infections or problems include difficulty in breathing and increased secretions.	0 1 2 3
Chronic pain	This is usually experienced as chronic tingling, burning or dull aches. It may occur in an area that has little to no feeling.	0 1 2 3
Joint and muscle pain	This includes pain in specific muscle groups or joints. People who must overuse a particular muscle group, such as shoulder muscles, or who put too much strain on their joints are at risk of developing pain.	0 1 2 3

For the following 16 health problems, please rate how much each one affected your activities and independence in the last 3 months. If you have not experienced a secondary condition in the last 3 months or if it is an insignificant problem for you, please circle ''0.'' Use the following scale to rate each of the secondary conditions.

0 ¼ NOT experienced in the last 3 months or is an insignificant problem.

1 ¼ MILD or INFREQUENT problem.

Appendix 11: SCIM-SR

SCIM – Spinal Cord Independence Measure
(Version III, Self-report 2013)

ADDRESSOGRAPH

This section asks about functioning in activities of daily living. For each item, please check the box next to the statement that best reflects **your current situation**. Please read the text carefully and only check one box in each section.

1. Eating and drinking

0. I need artificial feeding or a stomach tube
0. I need total assistance with eating/drinking
1. I need partial assistance with eating/drinking or for putting on/taking off adaptive devices
2. I eat/drink independently, but I need adaptive devices or assistance for cutting food, pouring drinks or opening containers
3. I eat/drink independently without assistance or adaptive devices

2. (a) Washing your upper body and head

Washing your upper body and head includes soaping and drying, and using a water tap.

0. I need total assistance
1. I need partial assistance
2. I am independent but need adaptive devices or specific equipment (e.g., bars, chair)
3. I am independent and do not need adaptive devices or specific equipment

(b) Washing your lower body

Washing your lower body includes soaping and drying, and using a water tap.

0. I need total assistance
1. I need partial assistance
2. I am independent but need adaptive devices or specific equipment (e.g., bars, chair)
3. I am independent and do not need adaptive devices or specific equipment

3. (a) Dressing your upper body

Dressing the upper body includes putting on and taking off clothes like t-shirts, blouses, shirts, bras, shawls, or orthoses (e.g., arm splint, neck brace, corset)

Easy-to-dress clothes are those without buttons, zippers, or laces.

Difficult-to-dress clothes are those with buttons, zippers, or laces.

0. I need total assistance
1. I need partial assistance, even with easy-to-dress clothes
2. I do not need assistance with easy-to-dress clothes, but I need adaptive devices or specific equipment
3. I am independent with easy-to-dress clothes and only need assistance or adaptive devices or a specific setting with difficult-to-dress clothes
4. I am completely independent

Version: 17Dec2014

FACILITY NAME	ADDRESSOGRAPH
SCIM – Spinal Cord Independence Measure **(Version III, Self-report 2013)**	

(b) Dressing your <u>lower body</u>

Dressing the lower body includes putting on and taking off clothes like shorts, trousers, shoes, socks, belts, or orthoses (e.g., leg splint)

Easy-to-dress clothes are those without buttons, zippers, or laces.

Difficult-to-dress clothes are those with buttons, zippers, or laces.

0. I need total assistance
1. I need partial assistance, even with easy-to-dress clothes
2. I do not need assistance with easy-to-dress clothes, but I need adaptive devices or specific equipment
3. I am independent with easy-to-dress clothes and only need assistance or adaptive devices or a specific setting with difficult-to-dress clothes
4. I am completely independent

4. Grooming

Please think about activities such as washing hands and face, brushing teeth, combing hair, shaving, or applying makeup

0. I need total assistance
1. I need partial assistance
2. I am independent with adaptive devices
3. I am independent without adaptive devices

5. Breathing

Please check only one box, depending on whether or not you need a respiratory (tracheal) tube.

I need a respiratory (tracheal) tube...

0. as well as permanent or from time to time assisted ventilation
2. as well as extra oxygen and a lot of assistance in coughing or respiratory tube management
4. as well as little assistance in coughing or respiratory tube management

I do not need a respiratory (tracheal) tube...

6. but I need extra oxygen or a lot of assistance in coughing or a mask (e.g., positive end-expiratory pressure (PEEP)) or assisted ventilation from time to time (e.g., bilevel positive airway pressure (BIPAP))
8. and only little assistance or stimulation for coughing
10. and can breathe and cough independently without any assistance or adaptive device

FACILITY NAME	ADDRESSOGRAPH
SCIM – Spinal Cord Independence Measure **(Version III, Self-report 2013)**	

6. Bladder management

Please think about the way you empty your bladder. [Scoring of item 6: see appendix A]

(a) Use of an indwelling catheter

0. Yes → Please go to question 7a
1. No → Please also answer questions 6b and 6c

(b) Intermittent catheterization

0. I need total assistance
1. I do it myself with assistance (self-catheterization)
2. I do it myself without assistance (self-catheterization)
3. I do not use it

(c) Use of external drainage instruments (e.g., condom catheter, diapers, sanitary napkins)

0. I need total assistance for using them
1. I need partial assistance for using them
2. I use them without assistance
3. I am continent with urine and do not use external drainage instruments

7. Bowel management *[scoring of item 7: see appendix B]*

(a) Do you need assistance with bowel management (e.g., for applying suppositories)?

0. Yes
1. No

(b) My bowel movements are...

0. irregular or seldom (less than once in 3 days)
1. regular (at least once every 3 days)

(c) Faecal incontinence ('accidents') happens...

0. twice a month or more
1. once a month
2. not at all

SCIM – Spinal Cord Independence Measure
(Version III, Self-report 2013)

ADDRESSOGRAPH

8. Using the toilet

Please think about the use of the toilet, cleaning your genital area and hands, putting on and taking off clothes, and the use of sanitary napkins or diapers.

0. I need total assistance
1. I need partial assistance and cannot clean myself
2. I need partial assistance but can clean myself
4. I do not need assistance but I need adaptive devices (e.g., bars) or a special setting (e.g., wheelchair accessible toilet)
5. I do not need any assistance, adaptive devices or a special setting

9. How many of the following four activities can you perform without assistance or electrical aids

- ***turning your upper body in bed***
- ***turning your lower body in bed***
- ***sitting up in a bed***
- ***doing push-ups in wheelchair (with or without adaptive devices)***

0. none, I need assistance in all these activities
2. one
4. two or three
6. all of them

10. Transfers from the bed to the wheelchair

0. I need total assistance
1. I need partial assistance, supervision or adaptive devices (e.g., sliding board)
2. I do not need any assistance or adaptive devices
2. I do not use a wheelchair

11. Transfers from the wheelchair to the toilet/tub

Transferring also includes transfers from the wheelchair or bed to a toilet wheelchair

0. I need total assistance
1. I need partial assistance, supervision or adaptive devices (e.g., grab-bars)
2. I do not need any assistance or adaptive devices
2. I do not use a wheelchair

Version: 17Dec2014

SCIM – Spinal Cord Independence Measure
(Version III, Self-report 2013)

ADDRESSOGRAPH

12. Moving around <u>indoors</u>

Please check only one box, depending on whether or not you usually use a wheelchair or walk to move around indoors.

I use a wheelchair. To move around, I...

0. need total assistance
1. need an electric wheelchair or partial assistance to operate a manual wheelchair
2. am independent in a manual wheelchair

I walk indoors and I...

3. need supervision while walking (with or without walking aids)
4. walk with a walking frame or crutches, swinging forward with both feet at a time
5. walk with crutches or two canes, setting one foot before the other
6. walk with one cane
7. walk with a leg orthosis(es) only (e.g., leg splint)
8. walk without walking aids

13. Moving around <u>moderate distances (10 to 100 metres)</u>

Please check only one box, depending on whether or not you usually use a wheelchair or walk to move around moderate distances (10 to 100 meters).

I use a wheelchair. To move around, I...

0. need total assistance
1. need an electric wheelchair or partial assistance to operate a manual wheelchair
2. am independent in a manual wheelchair

I walk moderate distances and I...

3. need supervision while walking (with or without walking aids)
4. walk with a walking frame or crutches, swinging forward with both feet at a time
5. walk with crutches or two canes, setting one foot before the other
6. walk with one cane
7. walk with a leg orthosis(es) only (e.g., leg splint)
8. walk without walking aids

Version: 17Dec2014

FACILITY NAME

SCIM – Spinal Cord Independence Measure
(Version III, Self-report 2013)

ADDRESSOGRAPH

14. Moving around outdoors for <u>more than 100 metres</u>

Please check only one box, depending on whether or not you usually use a wheelchair or walk to move around outdoors for more than 100 metres.

I use a wheelchair. To move around, I...

0. need total assistance
1. need an electric wheelchair or partial assistance to operate a manual wheelchair
2. am independent in a manual wheelchair

I walk more than 100 metres and I...

3. need supervision while walking (with or without walking aids)
4. walk with a walking frame or crutches, swinging forward with both feet at a time
5. walk with crutches or two canes, setting one foot before the other
6. walk with one cane
7. walk with a leg orthosis(es) only (e.g., leg splint)
8. walk without walking aids

15. Going up and down stairs

Please check only one box, depending on whether or not you are able to go up and down stairs.

0. I am unable to go up and down stairs

I can go up and down at least 3 steps...

1. but only with assistance or supervision
2. but only with devices (e.g., handrail, crutch or cane)
3. without any assistance, supervision or devices

16. Transfers from the <u>wheelchair into the car</u>

Transfers also include putting the wheelchair into and taking it out of the car.

0. I need total assistance
1. I need partial assistance, supervision or adaptive devices
2. I do not need any assistance or adaptive devices
2. I do not use a wheelchair

FACILITY NAME

SCIM – Spinal Cord Independence Measure
(Version III, Self-report 2013)

ADDRESSOGRAPH

17. Transfers from the floor to the wheelchair

0. I need assistance
1. I do not need any assistance
1. I do not use a wheelchair

SCORING (for clinician to complete)

Please use the following tables for items 6 and 7.

Item 6

SCIM-SR Item			Score in SCIM-SR
6A	6B	6C	
0	Not relevant if 6A=0	Not relevant if 6A=0	0
1	0	0	6
1	0	1	6
1	0	2	6
1	0	3	6
1	1	0	6
1	1	1	6
1	1	2	6
1	1	3	6
1	2	0	6
1	2	1	6
1	2	2	9
1	2	3	11
1	3	0	6
1	3	1	6
1	3	2	13
1	3	3	15

Item 7

SCIM-SR Item			Score in SCIM-SR
7A	7B	7C	
Not relevant if 7B=0	0	Not relevant if 7B=0	0
0	1	1	5
0	1	2	5
1	1	1	8
1	1	2	10
0	1	0	5
1	1	0	5

Self-care subscale, Items 1-4 (0-20) ☐

Respiration and sphincter management subscale, Items 5-8 (0-40) ☐

Mobility subscale, Items 9-17 (0-40) ☐

TOTAL SCIM SCORE (0-100) ☐

Date SCIM Completed: ☐☐☐☐ / ☐☐ / ☐☐
YYYY MM DD

Enter as much of the date as is known. If no details available, check Unknown.

☐ Unknown

Clinician Name/Signature: _____

Appendix 12: Letter of editing

TO WHOM IT MAY CONCERN

This letter confirms that the dissertation with the title *Physical Activity Behaviour of Community Dwelling Persons with Traumatic Spinal Cord Injury in Cape Town, South Africa* by Aeysha Gabriels for the fulfilment of the requirements for the M Sc degree. A thesis submitted in fulfilment of the requirements for the degree of Master of Science in the Department of Physiotherapy, Faculty of Community and Health Sciences, University of the Western Cape has been edited for grammatical and structural concerns by the undersigned language professional. Neither the research content nor the author's intentions were altered in any way during the editing process. The responsibility lies with the author to effect changes and to attend to any anomalies indicated during the editing process. Reference checking was included. The editor's professional profile can be viewed on LinkedIn. (https://za.linkedin.com/in/gava-kassiem-a7569b39).

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