

UNIVERSITY OF THE WESTERN CAPE

Faculty of Community and Health Sciences

Doctoral Thesis

THE RISK FOR CARDIOVASCULAR DISEASE FOLLOWING TRAUMATIC SPINAL CORD INJURIES IN THE CAPE METROPOLITAN IN SOUTH AFRICA

Student Name: Marc Anton Naidoo

Student number: 2026917

Type of Thesis: Doctoral Thesis

Degree: Ph.D.

Department: Physiotherapy

Supervisor: Prof J.S. Phillips

Date: 16 November 2018

Keywords: Cardiovascular disease, traumatic spinal cord injury, physical activity, community reintegration, risk behaviour

ABSTRACT

Given the devastating and debilitating impact of spinal cord injuries (SCI) globally and the effects on any population, its impact extends far beyond just the victim to people and institutions surrounding them and supporting them post-injury. Of growing concern is the increased risk that individuals with SCI have been seen to have a three-fold greater risk of developing cardio-vascular disease (CVD) than their able-bodied counterparts. Prevention strategies to curtail the onset of CVD in the SCI population is limited, and often developed for individuals from developed countries. The overall aim of this study was to assess and explore the need to implement CVD prevention programmes in a regional South African population with individuals after sustaining a traumatic spinal cord injury (TSCI). The study employed a mixed methods approach and was conducted in four (4) phases. Permission and ethics clearance were obtained from the Research Ethics Committee at the University of the Western Cape (UWC) and the Western Cape Department of Health. Phase One of the study utilized a questionnaire to collect TSCI incidence data of which 108 of the eligible 132 cases consented to take part in the study. The demographic findings of this study indicated that a person sustaining a TSCI in the Cape Metropolitan area in South Africa is most likely to be a male, young (20 to 29 years of age), from a Black African or Coloured race group and living in the Cape Flats suburbs. The male to female ratio was 6.2:1. The main cause of TSCI was assault at 58.33% (n=63) with males accounting for the majority of cases (88.89%, n=65). According to the AIS classification, ASIA A and D were the most common classification seen in 38.89% (n=42) and 39.81% (n=43) of the cohort respectively. Phase Two utilized a questionnaire and looked at CVD risk factors of the original cohort. A large portion of the cohort was engaged in high-risk behaviours, i.e.

smoking and alcohol consumption. A low number of individuals reported a baseline history of hypertension diagnosis prior to their TSCI (5.56%, n=6). Phase Three of the study employed semi-structured interviews and a focus group discussion to explore the experiences of persons with a TSCI regarding their ability to be physically active once reintegrated back into the community. Despite understanding the associated benefits of physical activity, several barriers to being physically active were reported; factors within their homes, access within their community, and transportation. The present study's findings illustrated a growing concern among the SCI population for increased risk for developing CVD due to decreased physical activity. Phase Four of the study utilised a scoping review to identify CVD prevention programmes for individuals with a TSCI. Physical activity has been shown to have numerous health benefits of which reducing the risk of CVD is one. Engaging in physical activity, whether it be structured, unstructured or through a sporting activity can play a major role in combating the onset of CVD. Other tools used in reducing the onset of CVD were seen to be self-management strategies of which contrayer views were seen both for and against their use. Conclusion: Better education during the rehabilitation phase might be a key component to individuals with TSCI injury making more informed decisions about prioritising physical activity as they attempt to reintegrate back into their respective communities. The removal of socio-environmental barriers could allow motivated TSCI individuals better access to choosing how to increase their physical activity levels.

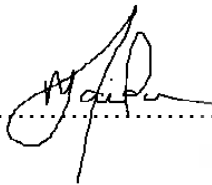
DECLARATION

I hereby declare that **“THE RISK FOR CARDIOVASCULAR DISEASE FOLLOWING TRAUMATIC SPINAL CORD INJURIES IN THE CAPE METROPOLITAN IN SOUTH AFRICA”** is my own work, that it has not been submitted, or part of it, for any degree of examination at any other university, and that all sources I have used or quoted have been indicated and acknowledged by means of complete references.

Marc Anton Naidoo

16 November 2018

Signature.....



Witness:



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.....
Prof J.S. Phillips (supervisor)

DEDICATION

To my amazing wife, Robynn and daughter, Kai Grace, thank you for your patience and longsuffering during this challenging journey. You continue to be my strength and inspiration when pursuing uncharted territory. This accomplishment is every much yours as it is mine. May it unlock doors for us all as we, together, seek to impact our circles of influence and change this country for the better. I am eternally grateful and privileged to be sharing my life journey with you and love you both to the moon and back.



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ACKNOWLEDGEMENTS

I am only able to achieve what I have because I have been able to stand on the shoulders of the giants who have gone before me. I am truly indebted to my supervisor, Prof Julie Phillips, for her belief in me and constant guidance, encouragement and critical engagement throughout this process. You are truly a light in this world and I believe our paths have crossed for so much more than this. You are more than just my supervisor. You are a dear friend who has been a pillar of strength to lean on during difficult times. This thesis would not have been possible without you pushing me to 'believe' again.

To my father, Prof Anthony Naidoo, who continues to be my example of 'true leadership'. Thank you for teaching me how to step up as a man and face all of life's challenges head on. Your life story continues to inspire me and gives me motivation to push beyond the "I" and consider the "we". I am so grateful for your wisdom and for teaching me to be mindful. You have taught me that community matters and this has spurred a desire in me to see our communities change. Thank you pops.

To my business partner and dear friend, Leron Hector, we have done so much over the years and your positivity and pursuit for impact has challenged me in more ways than you can imagine. Thank you for making the journey easier and worthwhile. May we together continue to change the world.

My sincere appreciation goes to my entire family, especially my late mother, Charmaine, stepmother, Charmaine, my mother-in-law, Esme, and late father-in-law, Kevin, and my brother, Nathan, and sister-in-law, Adrienne. You all have contributed to my development as a son, brother, family member, father and friend. As iron sharpens iron, you have sharpened me. You all unselfishly supported me with whatever was necessary to achieve my goal and make another dream come true. Thank you.

My amazing wife, Robynn and daughter, Kai Grace, who sacrificed with me to achieve my goal. Thanks for your understanding and granting me the opportunity to be 'absent' at times. I am looking forward to the next chapter where I can be 'present' and enjoy all the milestones together. I am proud to be called your husband and father, and am so excited for all the adventures we are going to be embarking on. May we write an amazing story together. Love you more than words can express.



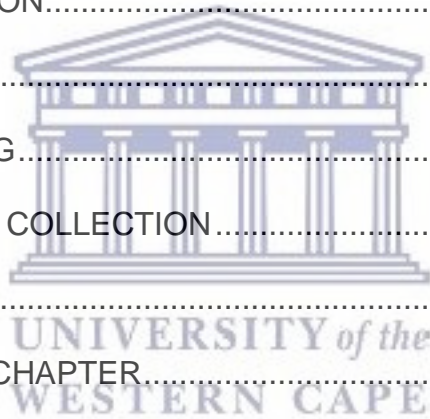
Above all, I am deeply grateful to God who continues to bless me beyond my expectations. May I walk with Your grace to carry all that You have entrusted me with and embody the ethos of 'blessed to be a blessing'.

We can't do everything, but we can do something.

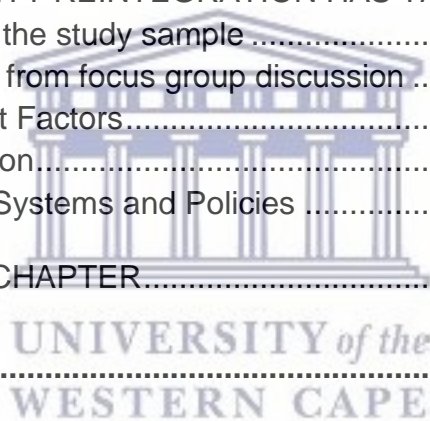
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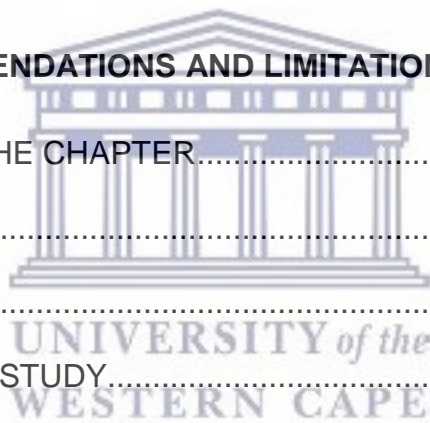
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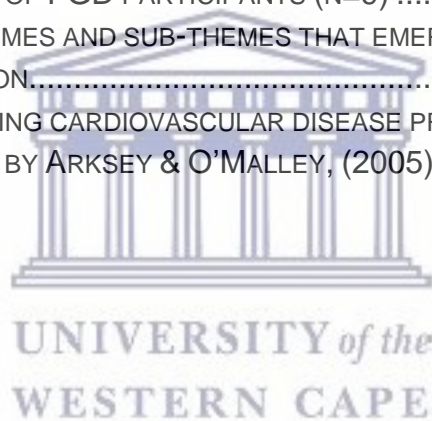
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CHAPTER 1

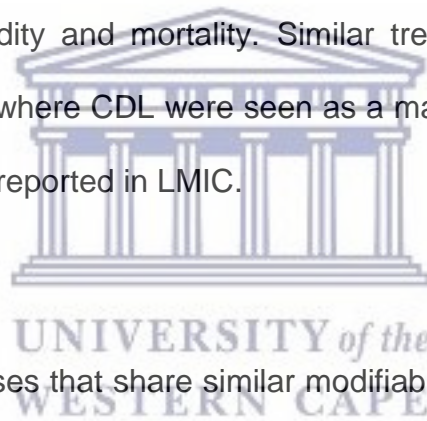
INTRODUCTION

1.1 INTRODUCTION TO THE CHAPTER

The present study investigated the need to implement cardiovascular disease (CVD) prevention programmes for individuals from the Western Cape metropolitan area of South Africa who sustained a traumatic spinal cord injury (TSCI). It has been reported that individuals living with spinal cord injuries (SCI) have an enhanced risk of developing CVD compared to their able-bodied counterparts (Cragg, Noonan, Krassioukov, & Borisoff, 2013). In addition to documenting the incidence of TSCI, CVD risks were assessed at the time of the injury to ascertain how this profile manifested and changed over a period of time. This chapter contextualises the rationale of the study highlighting international and local demographics regarding TSCI, the factors associated with CVD and the risks associated with these non-communicable diseases (NCDs) or this particular segment of the population. The aim of the study is presented, and the specific aims and objectives are delineated. The significance of the study lies in understanding the CVD risk profile associated with individuals who sustained a TSCI and identifying the facilitators and barriers that influence individuals' abilities to be physically active in their respective communities. The chapter ends with the definitions of terms salient to the study and the abbreviations used in the dissertation.

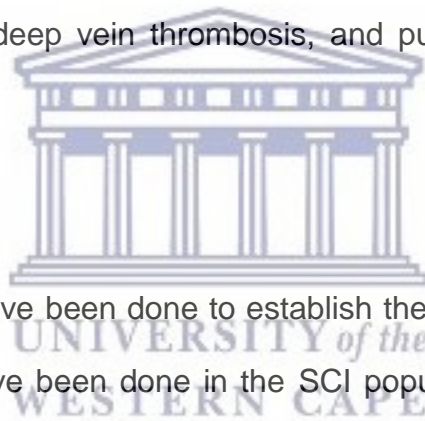
1.2 BACKGROUND TO THE STUDY

The disease profile of the world population is changing rapidly, especially in low- and middle-income countries (LMIC). In 2005, the World Health Organisation (WHO) reported that 60% of the deaths in the world were attributable to chronic diseases of lifestyle (CDL) (WHO, 2005). The 35 million deaths from CDL in 2005 were double the number of deaths for all infectious diseases (HIV/AIDS, tuberculosis, and malaria), maternal and perinatal conditions, and nutritional deficiencies combined. Approximately four out of five deaths due CDL occurred in LMIC. The WHO (2018) highlighted the enormous global burden of disease but stated that common risk factors were in fact largely modifiable and action could be taken to reduce the relevant morbidity and mortality. Similar trends were observed in the recent WHO report (2018) where CDL were seen as a major cause of death globally with higher numbers being reported in LMIC.



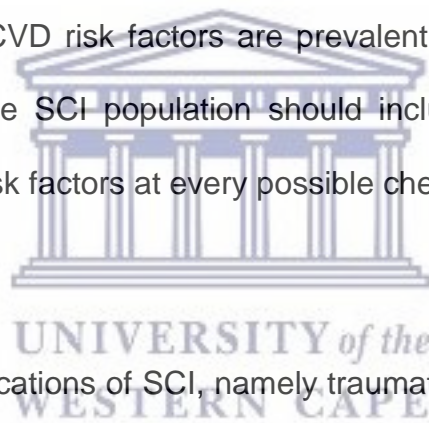
CDLs are a group of diseases that share similar modifiable risk factors as a result of exposure, over many decades, to unhealthy habits. Some of these unhealthy habits include things like smoking, eating an unhealthy diet, and lack of regular exercise. The major risk factors are tobacco addiction, high blood pressure, diabetes, high blood cholesterol, and subsequent obesity due to unhealthy eating habits. The consequences being the development of various long-term disease processes high mortality rates attributed to tobacco- and nutrition-induced cancers, chronic bronchitis, strokes, heart attacks, and many others. These diseases are known internationally as 'non-communicable diseases' (NCDs) or 'degenerative diseases' (Nash & Mendez, 2007). One of the most prevalent chronic diseases of lifestyle is cardiovascular disease (CVD) (Lloyd-Jones et al., 2010). It has been reported that

approximately one-half of chronic disease deaths in 2010 were credited to CVD (Centers for Disease Control and Prevention, 2012). Deaths due to chronic diseases were projected to increase by 17% by 2015 (WHO, 2005). This means that of the projected 64 million people who would die in 2015, 41 million would die of a chronic disease. The WHO recently confirmed these 2015 projections (WHO, 2018) citing that an estimated 17.9 million people died from CVDs in 2016, representing 31% of all global deaths. Furthermore out of the 17 million premature deaths due to noncommunicable diseases in 2015, 82% were in low- and middle-income countries, and 37% were caused by CVDs. The term CVD includes coronary heart disease, cerebrovascular disease, peripheral arterial disease, rheumatic heart disease, congenital heart disease, deep vein thrombosis, and pulmonary embolism among others.



While numerous studies have been done to establish the risk of CVD in the general population, few studies have been done in the SCI population. Some studies have been done in the United States of America (Bauman & Spungen, 2008; Nash & Mendez, 2007), Australia (Lidal et al., 2007; Soden et al., 2000), Sweden (Wahman et al, 2010) and the Netherlands (Adriaansen et al., 2016) to determine the CVD risks for the spinal cord injured populations. More recently Cragg et al. (2013) reported that individuals living with SCI have a three-fold greater risk of developing CVD than their able-bodied counterparts. It has not yet been conclusively established that the above named risks are increased (rather than just high, as in the general population) in the spinal cord injured population. Although some studies (Dyson-Hudson & Nash, 2009; Bauman & Spungen, 2008) have examined possible patient characteristics, causes, and co-morbidities of CVD risk after SCI, the

understanding of these risks factors is incomplete. It has been noted that a significant portion of individuals with spinal cord injuries are leading sedentary lifestyles (Nash, 2005) and are at risk of obesity (Weaver et al., 2007). In addition, diabetes mellitus, impaired fasting glucose, and insulin resistance had been projected to be common after SCI (Myers, Lee, & Kirarli, 2007) and this means that these risk factors are likely to lead to CVD in those with SCI. Wahman et al. (2010) proposed that systematic screening is of utmost importance to determine whether populations are at risk for selected diseases, such as CVD. Wahman et al. (2010) reported that evidence from developed countries suggests that individuals with a SCI are at risk of developing CVD but are often not referred for standard treatment. It is thus argued that if many CVD risk factors are prevalent in the general population, prevention strategies in the SCI population should include increasing awareness about screening for CVD risk factors at every possible check-up after injury.



There are two main classifications of SCI, namely traumatic spinal cord injury (TSCI) and non-traumatic SCI. In a global review, TSCI annual incidence rates yielded a value of 10.5 cases per 100,000 persons (95% CI, 8.6-12.84 cases/100,000). This incidence resulted in an estimated 768,473-790,695 cases of TSI worldwide each year (Kumar et al., 2018). Global research over the last decade has highlighted incidence and prevalence trends of persons with SCI being on the increase (Kumar et al., 2018; Cripps et al., 2011; Hagen et al., 2009; Wyndaele & Wyndaele, 2006). The main etiology for these injuries was found to be motor vehicle accidents (MVA), falls, violence and sports injuries. SCI encompasses several chronic conditions and secondary complications, e.g., paralysis, immobilisation, pressure sores and urinary tract infections (Dryden et al., 2004). Globally, the rise in incidence of SCI has been

associated with motor vehicle injuries and crime related cases (Kumar et al., 2018). In South Africa, this significant increase in the number of TSCI is caused by violence, sports injuries and motor vehicle accidents (Joseph et al., 2015; Maclachlan, 2012; Hart & Williams, 1994).

The health profile of South Africa is thought to be undergoing a noteworthy transition. There is limited data on the incidence and mortality of SCI in South Africa. It is postulated that the socio-economic and political climates are the main determinants hampering the significant reduction of this highly disabling health condition. Therefore, crime related injuries remain a major problem and exception to local context (Joseph et al., 2015; Maclachlan, 2012; Connor & Bryer, 2006). The increase in SCI in both national and international contexts greatly impacts not only the individual injured, but also their immediate family for the provision of support, and the private sector and National Government for the provision of long-term health care and financial support (Pickett, Campos-Benitez, Keller, & Dunggal, 2006). Given these assumptions and empirical evidence, it is essential to investigate various aspects of the epidemiological profile of SCI in order to plan and implement appropriate health care interventions and disease strategies.

SCI could be associated with significant functional impairment in the areas of self-care and mobility (McKinley, Huang, & Tewksbury, 2000). It is considered to be a devastating and debilitating condition that is prevalent in all regions of the world (Wyndaele & Wyndaele, 2006; Ackery, Tator, & Krassioukov, 2004). It is seen, however, to be more of an issue in developing countries, like South Africa, where

nationwide infrastructure and resources for rehabilitation programmes are underdeveloped. This results in this population group ending up being totally dependent on a system that cannot support them (Joseph et al., 2017; Couris et al., 2010; Pickett et al., 2006; Dryden et al., 2003).

The consequences of a SCI are multi-faceted and multi-factorial in nature. Not only does the SCI lead to disability and result from trauma to the spinal cord, but also it further presents in a very individualised and patient-specific manner (Rauch et al., 2011). Afflictions such as respiratory disorders, septicemia, and urinary tract infections have historically been major causes of premature death after spinal cord injuries (Whiteneck et al., 1992). Since the development of modern, comprehensive, evidence-based rehabilitation and medical care, persons with spinal cord injuries generally live longer and thus age with their disabilities. Survival after the SCI is dependent on access to adequate care and rehabilitation and differs substantially between countries (Cripps et al., 2011). The increased long-term survival in the SCI population as a whole warrants attention to be given to both new challenges during the post-acute rehabilitation phase and during life-long follow-up. Age-related issues in persons with spinal cord injuries are still not sufficiently elucidated (Cripps et al., 2011).

Research of SCI in South Africa has identified males, between 16-30 years of age from poor socio-economic background as the most common survivors (Pefile, Mothabeng & Naidoo, 2018; Joseph et al., 2015). The expectation is that they still have future prospects of living a long life with very few possibilities of returning to

their previous level of functioning, namely social integration, but specifically returning to productive living.

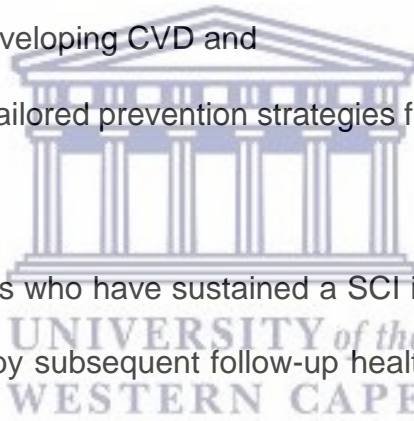
Physical inactivity has been reported among the most frequent risk factors for mortality in the general population (WHO, 2010). It has been suggested as a specific risk factor for CVD in SCI population (Bauman & Spungen 2008; Myers et al., 2007). Physical inactivity levels in the SCI population have been further reported to be alarmingly high (Martin Ginis, Jetha, Mack, & Hetz, 2010). It is an extreme example of deconditioning or movement deprivation. An increase in physical activity has been shown to have numerous benefits for individuals with SCI specially in decreasing it (Buchholz et al., 2009). These benefits include enhanced cardiovascular, respiratory and muscle function, as well as improved bone health (Wolfe et al., 2012). The assumption is that adults with a TSCI have a decreased level of physical activity following their community reintegration, limited access to resources essential for their engagement in health promotion activities, and an increased risk for developing CVD. Physical activity has been identified as not only a preventative strategy for the development of CVD but also necessary in the cost effective management of CVD.

1.3 PROBLEM STATEMENT

It has been widely reported that the epidemiological profile of persons with SCI is poorly recorded in South Africa. While numerous studies have been done to establish the profile of individuals with TSCI (WHO, 2013), limited studies exist from developing countries. It has, however, been reported that survivors of traumatic SCI in South Africa mostly involve the male gender, between the ages of 16-30 years of

age and of poor socio-economic background (Pefile et al., 2018; Joseph et al., 2015). As a result of the young age of the SCI population in South Africa, the expectation is that they have a prospect of a long lifespan with very few possibilities of returning to their previous level of functioning. With the prospect of a long lifespan individuals with TSCI are aging with their condition, putting them at risk for developing diseases related to ageing such as CVD. The assumptions held by the researcher are that adult clients with TSCI would have:

- A decrease level of physical activity depending on the severity of the injury,
- Limited access to resources essential for their engagement in health promotion activities,
- An increased risk for developing CVD and
- An increased need for tailored prevention strategies for CVD.



The ultimate goal of persons who have sustained a SCI is therefore integration back into society, accompanied by subsequent follow-up health checks that take place at local community healthcare centres. The follow-up health checks would be crucial in identifying CVD risks prior to their development and assist in better management of these conditions should they arise in the SCI population. A barrier to community reintegration stems from an uncoordinated rehabilitation programme that starts at tertiary facilities all the way to community-based rehabilitation. The poor service delivery often seen in both the in-patient and out-patient setting clearly highlights the absence of a systematic approach to the total management of SCI in South Africa. This results in very few people being able to return to or reintegrate back into work (Joseph et al., 2015). When poor service delivery experienced by the SCI population in South Africa is coupled with the prevalence of CVDs, it can be seen how this

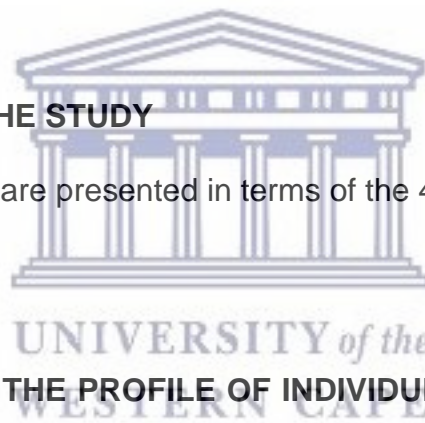
specific segment of the population might be doubly disadvantaged in not just the short term functional parameters, but also in the long term chronic medical conditions. Physical activity is therefore seen as a useful and cost effective tool to curtail the development and management of CVD in this population.

1.4 AIM OF THE STUDY

The overall aim of this study was to investigate and explore the need for the implementation of CVD prevention programmes after sustaining a TSCI in a regional South African population.

1.5 OBJECTIVES OF THE STUDY

The objectives of the study are presented in terms of the 4 phases of the study:



PHASE 1: TO DESCRIBE THE PROFILE OF INDIVIDUALS WITH A TRAUMATIC SPINAL CORD INJURY IN THE CAPE METROPOLITAN AREA, SOUTH AFRICA

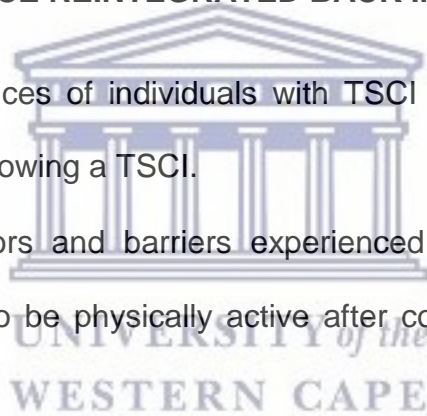
- To determine the socio-demographic profile of individuals who have sustained a TSCI in the Cape Metropolitan Area, South Africa.
- To determine the causes and describe the clinical classification of TSCI in the Cape Metropolitan area.

PHASE 2: TO DETERMINE THE CARDIOVASCULAR DISEASE RISK PROFILE OF INDIVIDUALS WHO SUSTAINED A TRAUMATIC SPINAL CORD INJURY IN THE CAPE METROPOLITAN AREA, SOUTH AFRICA

- To determine risk behaviours engaged in by the incidence cohort linked to CVD risks, specifically tobacco cigarette use, and alcohol consumption.
- To determine the history of raised blood pressure in the incidence cohort.
- To determine the factors associated with CVD risks, i.e., socio-demographic and health-related factors.
- To determine changes to individuals CVD risk profile one year after TSCI injury.

PHASE 3: TO EXPLORE THE EXPERIENCES OF PERSONS WITH A TRAUMATIC SPINAL CORD INJURY REGARDING THEIR ABILITY TO BE PHYSICALLY ACTIVE ONCE REINTEGRATED BACK INTO THE COMMUNITY

- To explore the experiences of individuals with TSCI regarding physical activity and how it is affected following a TSCI.
- To explore the facilitators and barriers experienced by individuals with TSCI influencing their ability to be physically active after community reintegration has taken place.



PHASE 4: TO IDENTIFY CARDIOVASCULAR DISEASE PREVENTION PROGRAMMES FOR INDIVIDUALS WITH A TRAUMATIC SPINAL CORD INJURY

- To identify CVD prevention programmes specifically for individuals who have had a TSCI.
- To determine key barriers and facilitators affecting access to CVD healthcare information and services regarding persons with a TSCI.

1.6 SIGNIFICANCE OF THE STUDY

The epidemiological profile of patients living with TSCI, who survived the initial ordeal of the devastating event, is poorly recorded and understood in South Africa. However, a few studies provided some evidence on the etiology of TSCI in South Africa (Joseph et al., 2015; Maclachlan, 2012; Velmahos et al., 1995; Hart & Williams, 1994), which is a different profile to that of other developing countries. This research project will present data with regard to the risk profile of individuals with TSCI for CVD, and highlight the importance of awareness to screening for CVDs post-injury. Annual check-ups may afford healthcare practitioners with a unique opportunity to perform screenings and recommend therapeutic lifestyle changes, and educate individuals with TSCI about the need to adopt a healthier lifestyle as countermeasures to their risks for developing CVD. This will help to illuminate the need for a coordinated healthcare system and improved communication between different governmental sectors as well as reorganise the resources allocation for this marginalised and vulnerable population. Furthermore the results could identify gaps in the curriculum used in the training of healthcare professionals with regards to the subject matter and could assist in the development of a more responsive curriculum to prepare professionals to curtail the onset of CVD in the SCI population.

1.7 ABBREVIATIONS

In this study the following abbreviations will be used:

AIDS	Acquired Immune Deficiency Syndrome
AIS	The American Spinal Cord Injury Association Impairment Scale
ASCI	Acute Spinal Cord Injury

ASIA	The American Spinal Cord Injury Association
CDL	Chronic Disease of Lifestyle
CVD	Cardiovascular Diseases
FIM	Functional Independence Measure
GSH	Groote Schuur Hospital
HBM	Health Belief Model
HIC	High Income Countries
HIV	Human Immunodeficiency Virus
HPT	Hypertension
ICF	The International Classification of Function
ISCOS	International Spinal Cord Society
LMIC	Low to Middle Income Countries
LTPA	Leisure time physical activity
MBI	Modified Bartel Index
MLIC	Middle to Low-Income Countries
MI	Myocardial Infarction
NCD	Non-Communicable Disease
NCPIC	National Centre for Injury Prevention and Control
NSCISC	National Spinal Cord Injury Statistical Centre



NTSCI	Non-traumatic Spinal Cord Injuries
RTA	Road Traffic Accident
SCI	Spinal Cord Injuries
SCT	Social Cognitive Theory
SEM	Socio-Ecological Model
SPSS	Statistical Package for the Social Sciences
TSCI	Traumatic Spinal Cord Injuries
TTM	Transtheoretical Model
TPB	Theory of Planned Behaviour
WCRC	Western Cape Rehabilitation Centre
WHO	World Health Organisation



The logo of the University of the Western Cape is centered on the page. It features a stylized classical building with a pediment and columns. Below the building, the text 'UNIVERSITY of the WESTERN CAPE' is written in a serif font, with 'UNIVERSITY' and 'WESTERN CAPE' in all caps and 'of the' in lowercase.

1.8 DEFINITION OF TERMS

The definitions of the following seminal terms used in this study are presented:

ASIA Impairment Scale (AIS): Based on the Frankel scale, this is a clinician-administered scale used to classify the severity (completeness) of injury in individuals with SCI. It identifies sensory and motor levels indicative of the highest spinal level demonstrating “unimpaired” function (Maynard et al., 1997).

Cardiovascular disease (CVD): Cardiovascular diseases (CVDs) are disorders of the heart and blood vessels and include coronary heart disease, cerebrovascular disease, rheumatic heart disease and other conditions (WHO, 2018).

Community reintegration: “Community (re-) integration after/with (physical) impairment or disability) is acquiring/resuming age-/gender-/culture-appropriate roles/status/activities, including independence/interdependence in decision making, and productive behaviours performed as part of multi-varied relationships with family, friends, and others in natural community settings” (Dijkers, 1998, p5).

Complete injury: This term is used when there is an absence of sensory and motor function in the lowest sacral segment (Maynard et al., 1997, p. 537).

Dermatome: This term refers to the area of the skin innervated by the sensory axons within each segmental nerve (root) (Maynard et al., 1997, p. 536).

Disability: This term refers to a difficulty in functioning at the body, person, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors (Leonardi Bickenbach, Ustun, Kostanjsek, & Chatterji, 2006, p. 1220).

International Classification of Functioning (ICF): is a classification of health and health-related domains (International Classification of Functioning, Disability and Health (ICF, 2018).

Incomplete injury: If partial preservation of sensory and/or motor functions is found below the neurological level and includes the lowest sacral segment, the injury is defined as incomplete. Sacral sensation includes sensation at the anal mucocutaneous junction as well as deep anal sensation. The test of motor function is the presence of voluntary contraction of the external anal sphincter upon digital examination (Maynard et al., 1997, p. 537).

Myotome: This term refers to the collection of muscle fibers innervated by the motor axons within each segmental nerve (root) (Maynard et al., 1997, p. 536).

Neurological level, sensory level and motor level: The first of these terms refers to the most caudal segment of the spinal cord with normal sensory and motor function on both sides of the body. In fact, the segments at which normal function is found often differ by side of body and in terms of sensory vs. motor testing. Thus, up to four different segments may be identified in determining the neurological level, i.e., R-sensory, L-sensory, R-motor, L-motor. In cases such as these, it is strongly recommended that each of these segments be separately recorded and that a single 'level' not be used, as this can be misleading in such cases. When the term Sensory Level is used, it refers to the most caudal segment of the spinal cord with normal sensory function on both sides of the body; the Motor Level is similarly defined with respect to motor function. These 'levels' are determined by neurological examination of: (1) a key sensory point within each of 28 dermatomes on the right and 28 dermatomes on the left side of the body, and (2) a key muscle within each of 10 myotomes on the right and 10 myotomes on the left side of the body (Maynard et al., 1997, p. 537).

Non-traumatic Spinal Cord Injury (NTSCI): This type of spinal cord injury usually involves an underlying pathology – such as infectious disease, tumor, musculoskeletal disease such as osteoarthritis, and congenital problems (WHO, 2013, p. 6).

Paraplegia: This term refers to impairment or loss of motor and/or sensory function in the thoracic, lumbar or sacral (but not cervical) segments of the spinal cord, secondary to damage of neural elements within the spinal canal. With paraplegia, arm functioning is spared, but, depending on the level of injury, the trunk, legs and pelvic organs may be involved. The term is used in referring to cauda equina and conus medullaris injuries, but not to lumbosacral plexus lesions or injury to peripheral nerves outside the neural canal (Maynard et al., 1997, p. 536).

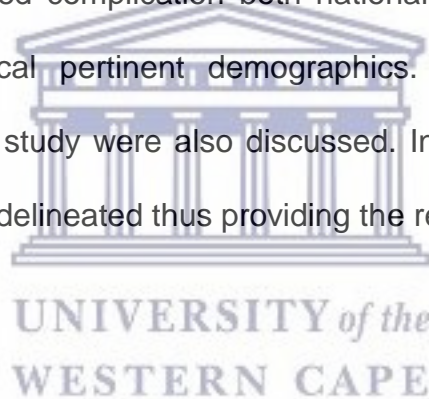
Physical activity: This type or kind of activity includes any bodily movement produced by the contraction of skeletal muscle that increases energy expenditure above a basal level that enhances life ("Glossary of Terms | Physical Activity | CDC", 2018).

Tetraplegia: This term refers to impairment or loss of motor and/or sensory function in the cervical segments of the spinal cord due to damage of neural elements within the spinal canal. Tetraplegia results in impairment of function in the arms as well as in the trunk, legs and pelvic organs. It does not include brachial plexus lesions or injury to peripheral nerves outside the neural canal (Maynard et al., 1997, p. 536).

Traumatic Spinal Cord Injury (TSCI): a lesion of traumatic nature within the spinal cord that results in the disruption of nerve fibre bundles that convey ascending sensory and descending motor information (Noe, Stapelfeldt, Parner, & Mikkelsen, 2016).

1.9 OVERVIEW OF THE ORGANISATION OF THE THESIS

This dissertation is presented in eight chapters. The first chapter highlighted the need for an incidence study of TSCI in a regional South African population as well as the necessity to identify the CVD risk profile of these individuals. SCI classification, management and associated complication both nationally and internationally were discussed, highlighting local pertinent demographics. The framework and the problem statement for this study were also discussed. In addition, study objectives and significance were also delineated thus providing the research focus of the study.



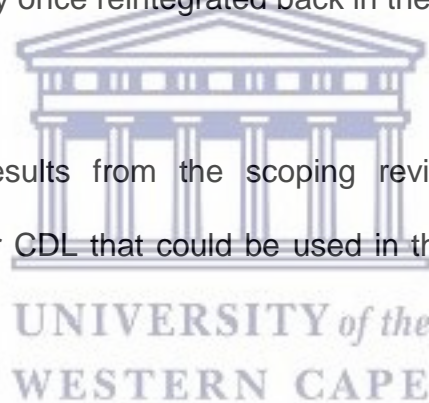
Chapter 2 provides a review of the pertinent literature in the field of TSCI and CVD risks. A large and differential body of research exists that has contributed to SCI and for this reason the literature review focuses mainly on the constructs pertinent to this study which are CVD in this population group.

In Chapter 3 the research method utilised in the study is described. The research problem and related hypotheses, sample used to gather the data from, the measuring instruments involved in the data gathering and the statistical methods used to analyse the data is presented.

Chapter 4 reported the results and outcomes of the quantitative data collected in the first phase of the study. The results include information related to the demographics, incidence of TSCI, CVD risk profile. Further, associations between TSCI and CVD are reported.

Chapter 5 reports the results and outcomes of the qualitative data collected from semi-structured interviews and focus group discussion as part of the second phase of the study. The results include information related to CVD risk one-year post discharge from GSH ASCI unit and explored individuals experienced facilitators and barriers to physically activity once reintegrated back in their respective communities.

Chapter 6 reports the results from the scoping review conducted to identify prevention programmes for CDL that could be used in the SCI population in South African context.



Chapter 7 provides an explication of the quantitative and qualitative results. The chapter unpacks and integrates the results and delineates the implications of the study.

Finally, Chapter 8 provides a summary of the study, the limitations and draws conclusions based on the findings. In addition, recommendations based on the main findings of the study are made.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION TO THE CHAPTER

This chapter sources competency texts and journals studies with the view to review current thinking and research findings in the arena of SCI, more specifically related to the intersection of traumatic spinal cord injuries (TSCI) and cardiovascular diseases (CVD) and the prevention thereof. This chapter will provide not only an analysis of the pertinent literature but will also attempt to explicate the study's focus on CVD risk profiles of individuals with TSCI in the Cape Metropolitan in South Africa. The keywords included in the search were spinal cord injury, traumatic spinal cord injury, epidemiology, chronic diseases of lifestyle, cardiovascular disease, cardiovascular prevention strategies, and cardiovascular prevention programmes. The search was performed in the following databases: EBSCOHost, Pubmed, ResearchGate, Science Direct, MEDLINE, CINAHL, Academic Search Premier, HEALTH SEARCH: Nursing/Academics Edition, MasterFILE Premier, ERIC, PsycARTICLES, AccessPhysiotherapy and SocINDEX.

2.2 SPINAL CORD INJURIES

A SCI is an injury to the spinal cord situated within the spinal column. Based on the etiology, SCIs can be divided into two main groups: non-traumatic spinal cord injuries (NTSCI) and traumatic spinal cord injuries (TSCI) (WHO, 2013). TSCI are defined as a lesion of traumatic nature within the spinal cord that results in the disruption of nerve fibre bundles that convey ascending sensory and descending

motor information (Noe et al., 2016). NTSCI is defined as the presence of a non-traumatic condition causing spinal cord dysfunction (Grassner et al., 2016). This resulting damage can be the result of infection, loss of blood supply, compression by a tumour or through slow degeneration of the spinal bones (vertebrae) such as in osteoarthritis.

The American Spinal Cord Injury Association (ASIA) (Marino et al., 2003) has developed a standardised classification system for SCI, called the ASIA Impairment Scale (AIS), to identify the degree of neural damage sustained following an injury. The ASIA impairment scale has been strongly recommended to all who aim to record neurological impairments of the spinal cord in a standardised manner. It has replaced the Frankel Classification, which was previously used to classify SCI (Maynard et al., 1997). The AIS's neurological examination is based on clinical examination of motor and sensory function and is assessed separately. The required elements are used in determining the sensory/motor/neurological levels, in generating scores to characterise sensory/motor functioning and in determining completeness of the injury. The sensory examination is completed through the testing of a key point in each of the 28 dermatomes on both sides of the body. The motor component assessed is completed through the testing of a key muscle, on both sides of the body, in the 10-paired myotomes (Marino et al., 2003). Furthermore, the grading of the impairment is done using the ASIA impairment scale (AIS) (Maynard et al., 1997) and is delineated in Table 2.1. In the grading ASIA, A implies a complete injury, whereas ASIA B – D describes incomplete injuries.

Table 2.1 AIS (ASIA - impairment scale)

Grading	Descriptor
A=Complete	No sensory or motor function is preserved in the sacral segments S4-S5
B=Incomplete	Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5
C=Incomplete	Motor function is preserved below the neurological level, and more than half of key muscles below the neurological level have a muscle grade less than 3
D=Incomplete	Motor function is preserved below the neurological level, and at least half of key muscles below the neurological level have a muscle grade greater than or equal to 3
E=Normal	Sensory and motor function is normal

Source: (Maynard et al., 1997)

2.2.1 Epidemiology

Numerous studies have pointed to the challenge in comparing epidemiological findings of SCI of one country or continent with another due to differences in social structure, therapeutic procedures and data-gathering systems. This challenge was specifically highlighted for studies in Africa and Asia (Vasiliadis, 2012; Cripps et al., 2011). Furthermore, large variations in incidence, prevalence, gender distribution, mechanism of injury, level of injury, and completeness of injury have been reported from various parts of the world with regards to SCI (Cripps et al., 2011; Chiu et al., 2010; Van den Berg, Castellote, Mahillo-Fernandez, & de Pedro-Cuesta, 2010; Wyndaele & Wyndaele, 2006). Ackery et al. (2004) in their review suggested standardisation issues for comparison of epidemiological SCI studies but also noted that countries with similar economies tended to have similar injury patterns. Two years later Wyndaele and Wyndaele (2006) noted a similar need for standardised reporting of SCI for better international comparability. They further highlighted a lack

of information from Latin America, Africa and Asia. A few years afterwards, Chiu et al. (2010) also noted the same trend and indicated that the epidemiological characteristics of SCIs varied in different countries, but more specifically in regions with different economic levels or in different economic periods. More recently, Kumar et al. (2018) reached similar conclusions when they assessed the global epidemiology and worldwide volume for TSCI. Their systematic review found challenges in comparability of epidemiological data due to different study designs and data collection methods. Interesting to note was that they reported more studies from developing countries. The quality of researching emerging from developing countries also seemed to be improving, with some prospective, regional and national studies being reported from the African continent. They further reported that the proportion of patients with TSCI to be higher in low-middle income countries compared with high-income countries.



Osterthun, Post, & van Asbeck (2009) reported that within the general SCI population, TSCI accounted for the majority of SCI injuries, and that most of the studies on SCI were conducted with individuals with TSCI. More than ten years ago, Cripps et al. (2011) attempted to map the epidemiology of TSCI globally and found difficulty in determining valid population denominators useful for the identification and implementation of prevention strategies. Cripps et al.'s (2011) global mapping of SCI from TSCI causes by countries for the period 1959-2008, highlighted few studies from the African continent. Research findings were reported for South Africa, Zimbabwe, Nigeria and Sierra Leone as illustrated in Figure 2.1. Kumar et al. (2018) more recently reported new studies emerging from African countries like Ghana, Ethiopia, and Botswana, Nigeria and several from South Africa.

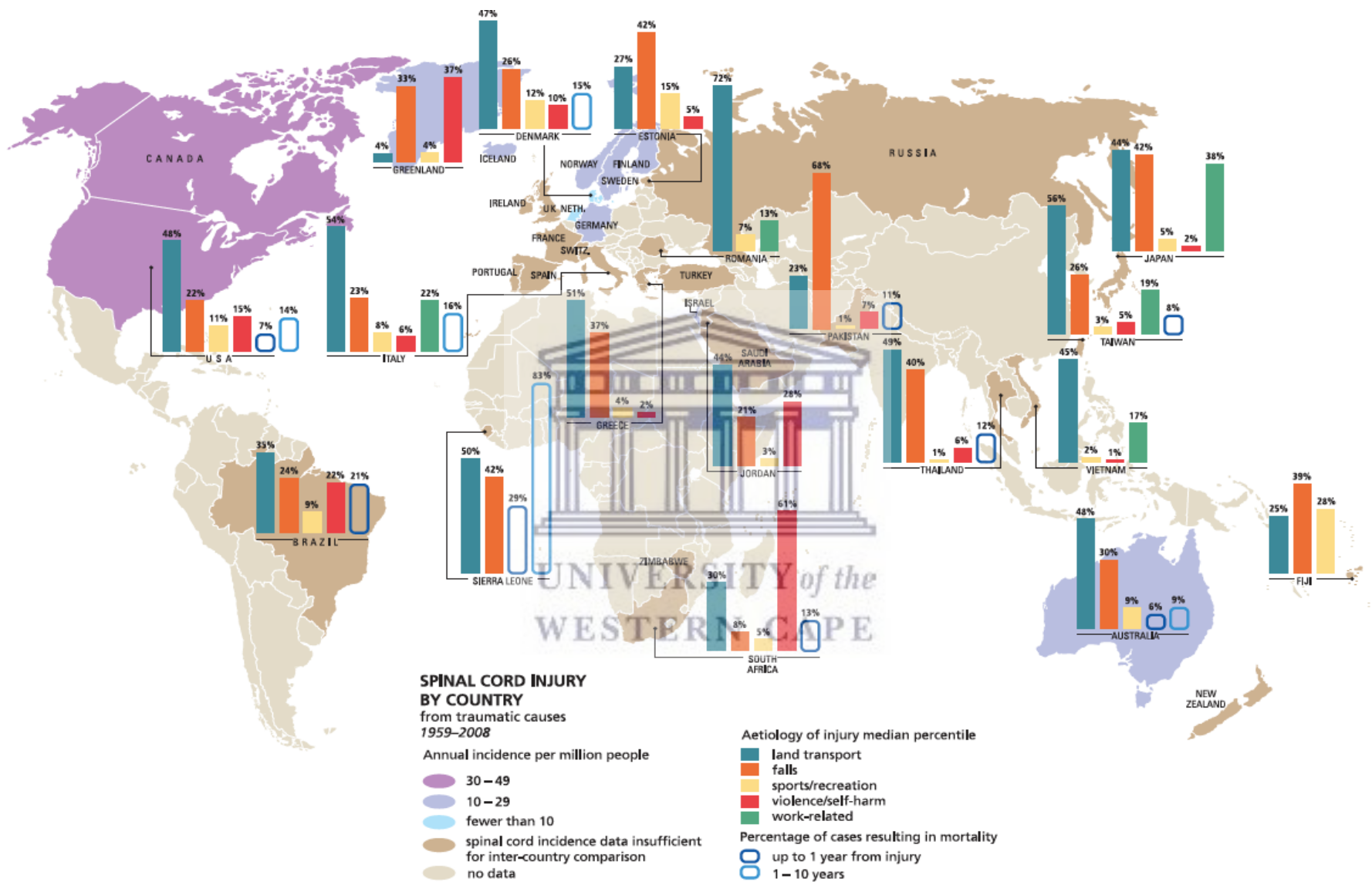


Figure 2.1 Global mapping of SCI from traumatic causes country 1959-2008 (Source: Cripps et al., 2011, p. 496)

The percentage of non-traumatic SCI (NTSCI) patients was also found to be significant. A previous study by Scivoletto, Farchi, Laurenza, and Molinari (2013) with 3,000 patients with SCI, reported that a third of patients with SCI had a NTSCI. It was further reported that older, retired females were higher in the NTSCI group than the TSCI group. As NTSCI patients were usually older, they usually had developed other medical conditions such as diabetes, cardiovascular and pulmonary diseases. These co-existing health problems could be seen to have resulted in a decrease in the efficiency of rehabilitation and in hampering improvement of long-term functionality of the NTSCI patients (New & Sundararajan, 2008). Due to this, patients with NTSCI and TSCI should be viewed as two distinct clinical entities, each entitled to independent rehabilitation strategies to maximise their functional recovery. This study looked specifically at TSCI only.



The sub-Saharan region on the African continent has produced limited publications on TSCIs and up to seven years ago was rarely mentioned in worldwide reviews (Draulans, Kiekens, Roel, & Peers, 2011). Several studies have emerged in Africa in recent years namely Nigeria (Obalum, Giwa, Adekoya-Cole, & Enweluzo, 2009), Ethiopia (Biluts et al., 2015), Botswana (Löfvenmark et al., 2015) and Ghana (Ametefe et al., 2016). Specifically, in South Africa, several studies have been conducted with SCI individuals that focused on NTSCI (Pefile et al., 2018) while others focused on TSCI (Sothmann, Stander, Kruger, & Dunn, 2015; Joseph et al., 2015; Maclachlan, 2012). Specifically, with regards to TSCI, two retrospective hospital-based studies were conducted more than two decades ago (Hart & William, 1994; Velmahos et al., 1995). Hart and William (1994) reviewed 616 SCI patients' files and reported that TSCI accounted for majority of the total SCI cases (89%).

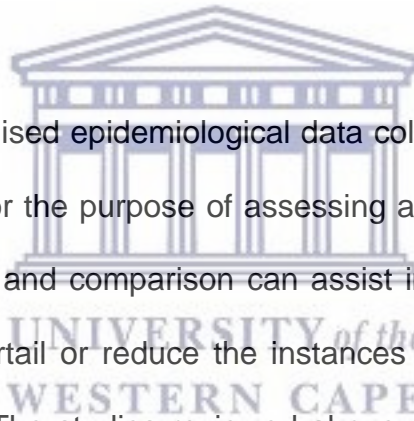
Velmahos et al. (1995) collected data from two hospitals and reported that violence was seen to be the most common cause of injury in their study's on 551 SCI cases. Seventeen years after these studies, a prospective descriptive study (Maclachlan, 2012) assessed the level of participation of persons with traumatic TSCI post rehabilitation. She found a person sustaining a TSCI, in the Cape Metropolitan area of the Western Cape Province, was most likely to be a young male (20 to 29 years old), of Coloured or Black African race and living in the Cape Flats suburbs. More recently, a prospective hospital based study (Joseph et al., 2015) investigated injury characteristics of TSCI patients and found the incidence rate of TSCI in a region of South Africa to be high when compared to previously postulated figures for the country. In a retrospective hospital-based study (Sothmann et al., 2015), investigated the epidemiology of acute spinal cord injuries over an eleven-year period in a tertiary hospital in South Africa. They reported that 2,042 patients were admitted to the acute spinal cord unit with an average of 185 admissions per year. The ratio of males to females was 5.25:1 and the largest age category was seen in the 21 – 30 year old group of patient (33.5%).

Additional information about the epidemiology of patients with SCI shows that paraplegia compared with tetraplegia has changed over the recent years. Previous studies reported the proportion of paraplegia to be up to 90%, whereas more recent reports show a decline in the SCI resulting in paraplegic and compared to an increase in tetraplegic (Wyndaele & Wyndaele, 2006; Ackery et al., 2004). In the Netherlands (van Asbeck, Post, & Pangalila, 2000) and the United States (Jackson, Dijkers, Devivo, & Poczatek, 2004) a high percentage of tetraplegia was reported at 57% and 54.1% respectively. Studies from more than ten years ago showed an

increase in complete SCI (Dahlberg et al., 2005; van Asbeck et al., 2000; Maharaj, 1996). Complete SCI accounted for 35% of the injuries in Canada (Pickett et al., 2006). Complete SCI were more prominent in the thoracic spine than in the lumbar and cervical segments of the spine. In Beijing, the proportion of SCIs that was complete was 67% over the past thirty years; this value was seen to decrease to 45% at the end of 2007 (Chun-xiam, Jian-jun, & Hong-jun, 2007). The decrease in complete SCI was suggested to be as a result of improved first aid technology, which allowed SCI patients to receive appropriate and timely treatment. Epidemiological data related to classification of TSCI in Africa reported by Draulans et al. (2011) found similar distributions of tetraplegic and paraplegic patients in Nigeria (Solagberu, 2002) and Senegal (Seye et al., 1993) with 46-54% respectively. Paraplegic patients were seen to be more common compared to tetraplegic patients in a different study conducted in Nigeria (30-170%, Obalum et al., 2009), and in South Africa (26-74%, Velmahanos et al., 1995; 75-25%, Hart & William, 1994). In Botswana, Löfvenmark et al. (2015) reported more tetraplegia than paraplegia. Gosselin and Coppotelli (2005) reported the highest percentage of complete spinal cord lesions compared to incomplete lesions (88-12%) in Sub-Saharan Africa. Specifically in South Africa, Sothmann et al. (2015) highlighted that 31.7% of patients had complete SCI and 68.3% had incomplete SCI. This trend seems to be consistent with previous studies highlighting an overall improvement in the acute management of SCI and subsequent severity locally.

Given the devastating and debilitating impact of SCI globally (WHO, 2013; Ackery et al., 2004) and the effects on a small population, it becomes important to note that the impact extends far beyond just the victim, to people and institutions surrounding

them and supporting them post-injury (WHO, 2013). The long-term consequences that extend beyond the precipitating event translate into personal and financial loss for the affected individual and their family. Furthermore, it exerts significant loss on the economy and healthcare system through lost productivity, revenue, and the substantial costs associated with long term care (WHO, 2013; Couris et al., 2010; Pickett et al., 2006; Dryden et al., 2003). Prevention is therefore considered to be the most effective means of combating SCI through targeted programmes and education aimed at population-at-risk (Pickett et al., 2006). Researching and understanding the SCI population is seen to be instrumental to this pre-emptive approach (WHO, 2013).




The importance of standardised epidemiological data collection has been highlighted above. This is necessary for the purpose of assessing and comparing global trends. Ultimately this assessment and comparison can assist in developing region specific prevention strategies to curtail or reduce the instances of TSCI, both in developed and developing countries. The studies reviewed above were mostly retrospective in nature. While studies from more than ten years ago highlighted difficulties in global comparison, specifically in Sub-Saharan Africa, more recent studies have seen an improvement in standardisation of reporting especially in developing countries making comparison more possible. Furthermore, there have been more population-based studies in Africa and one in South Africa. The strength of the current study is in its prospective longitudinal design. The data collected allowed for a more purposive analysis of the contextual factors in a developing country and highlighted the epidemiological data specifically in the Cape Metropolitan area in South Africa.

2.2.2 Incidence and Prevalence

Wyndaele and Wyndaele (2006) assert that research on the incidence and prevalence of SCI is crucial because of its high personal, bio-psychological impact as well as their significant short and long-term high socio-economic consequences. They noted further that incidence rates reflected the level of control of SCI and the possible need for improved prevention. Prevalence rates on the other hand had an impact on health care and on social and personal resources (Wyndaele & Wyndaele, 2006). This study was interested more in incidence rates as it was focused on CVD prevention and the need for its implementation in the TSCI population in a regional area in South Africa.

Incidence

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There have been several estimations of worldwide incidence of TSCI over the last three decades. Blumer and Quine (1996) in their international comparison estimated incidence to be between 13 and 33 cases per million. Almost ten years later, Jackson et al. (2004) reported an increase in the global incidence of SCIs, with the rate of incidence estimated at 15 to 40 cases per million worldwide, despite prevention initiatives. More than ten years ago Wyndaele and Wyndaele (2006) in their review reported TSCI incidence estimations to be between 10.4 and 83 per million persons, with the Netherlands reporting the lowest incidence estimations (14.5 cases per million) compared to Alaska, in the United States, reporting the highest (83 cases per million). Conclusions made by Wyndale and Wyndale (2006) on incidence globally was that it had remained more or less the same over the 30-year period review. This was because despite the number of cases increasing, the population had also grown proportionally. Conversely, lower incidence could result from greater mortality at the

site of the accident. Fitzharris, Cripps and Lee (2013) estimated the global incidence of SCI to be 23 cases per million. The WHO (2013) reported interesting trends when analysing the TSCI country-level incidence data. They estimated global SCI incidence to be 40 - 80 new cases per million per year, based on quality country-level incidence studies of SCI. New SCI cases were between 250 000 and 500 000 people globally. Incidence of TSCI was on the decline in some countries, but staying stable or on the incline in others. Incidence of SCI was more likely to occur in young adult males and in the elderly (WHO, 2013). Furlan et al. (2013) reviewed 64 articles published between 1950 and 2012 and found a large disparity of reported SCI incidence, which ranged between 8 to 246 cases per million persons. The majority of studies were from Europe and North America, while none were from Africa. Cripps et al. (2011) reported that the highest incidence of SCI was in North America while the lowest incidence was in Australia at 39 and 16 per million respectively. A more recent worldwide systematic review by Kumar et al. (2018) reviewed a total of 102 studies and reported an overall global incidence of TSCI of 10.5 cases per 100,000 persons (95% confidence interval, 597,213 - 939,732), resulting in an estimated 768,473 new cases of TSCI annually worldwide. The incidence of TSCI was higher in low- and middle-income countries (LMIC) (8.72 per 100,000 persons) compared with high-income countries (HIC) (13.69 per 100,000 persons). Africa was well represented in the last five years compared to 2013 reports from WHO (2013) and Furlan et al. (2013).

Wyndaele and Wyndaele (2006) in their worldwide literature survey, more than ten years ago, highlighted that most studies were found to be from Europe and North America. They reported the incidence rates in Europe to be from 13.9 – 19.4 per

million over a thirty year period, In Finland high numbers were reported with an annual SCI incidence of 28 per million being reported in 2005 (Dahlberg et al., 2005). In Norway, the SCI incidence rate increased considerably, with 6.2 per million reported from 1952 to 1956, to 26.3 per million from 1997 to 2001 (Hagen, Lie, Rekand, Gilhus, & Gronning, 2010). Ireland reported lower incidence rate of 11.5-13.3 per million per year (Smith et al., 2018). In Estonia, Sabre et al. (2013) reported the highest incidence rates of 39.7 per million. France reported an SCI incidence rate of 19.4 per million, or an average of 934 new cases each year (Albert & Ravaud, 2005). Knútsdóttir et al. (2012) reported a crude annual incidence in Iceland of 30 per million per year in 1975-1979, which decreased to 12.5 in 1995-1999 and increased to 33.5 in 2005-2009. This increase over five year intervals was seen to be statistically significant. Most of the studies reporting TSCI incidence were retrospective in nature. Cripps et al. (2011) reported an incidence rate of 16 per million in Western Europe, which is seen to be lower than the average reported for Europe by Wyndale and Wyndale (2006). Better standardisation of SCI reporting has lead to better comparison of data in recent years compared to older studies. More recently, Kumar et al. (2018) reported that the incidence of TSCI in Europe ranged from 3.4 per 100,000 (95% CI, 1.8 - 6.6 cases/100,000). The overall increase in trend could be as a result of increased survival rates at the scene of the accident and better medical management.

Cripps et al. (2011), in their literature review mapping global TSCI epidemiology, reported that North America had the highest average incidence according to WHO region, at 39 per million compared to Australia with the lowest average incidence at 15 per million. DeVivo (2012) supported the above-mentioned incidence rate findings

with an average incidence rate in the United States of 40 per million. He further highlighted that future projections would increase to 13 600 in 2020. The WHO (2013) proposed that the high incidence rate in USA could possibly be due to higher rates of violence seen. A study conducted in Canada highlighted an incidence of TSCIs in people aged 15 to 64 at 42.4 per million, and for people over the age of 65, at 51.4 per million between 1997 and 2001 (Kattail, Furlan, & Fehlings, 2009).

Rahimi-Movaghar et al. (2013) conducted a systematic review of the epidemiology of TSCI in developing countries, which included countries like Brazil, Afghanistan, Zimbabwe and South Africa. They reported an average SCI incidence of 25.5 per million per year which ranged from as little as 2.1 in Saudi Arabia to as much as 130.7 per million in Bulgaria. More than five years ago in Sub-Saharan Africa, Draulans et al. (2011) found limited trustworthy data concerning incidence and prevalence of SCI. They reported that the studies' methodology was often limited in that they always used hospital-based studies and none of them provided a survey of all admissions across the country. They purported that "correct data can only be obtained when the admission data of the country at large are at disposal and at the same time, the number of patients who never reached the hospital can be estimated" (Draulans et al., 2011, p. 1150). Despite the findings of Rahimi-Movaghar et al. (2013) regarding limited incidence and prevalence data being available in Africa, Kumar et al. (2018) recently reported several studies reporting TSCI incidence on the African continent. A five year retrospective, hospital-based study from north-east Tanzania reported the annual incidence for the Kilimanjaro region at more than 26 persons per million (Moshi, Sundelin, Sahlen, & Sörlin, 2017). In Botswana, a prospective hospital-based study reported an annual incidence rate of 13 per million

(Löfvenmark et al., 2015). In South Africa, four retrospective hospital-based studies were conducted in the last three decades, investigating injury characteristics of persons with SCI (Pefile et al., 2018; Sothmann et al., 2015; Velmahos et al, 1995; Hart & Williams, 1994). They, however, reported no estimate of the incidence rate. Joseph et al. (2015) in their recent TSCI prospective incidence study reported a high incidence rate of 75.6 per million persons, which puts South Africa in the upper percentile of incidence rates worldwide. Reasons for the high incidence rate alluded to by Joseph et al. (2015), were due to the high interpersonal violence. When comparing Joseph et al.'s (2015) incidence rates to another prospective study in Botswana (Löfvenmark et al. (2015), South Africa's incidence rate is seen to be an alarming five times more. Pefile et al. (2018) reported more recently that the average annual incidence rate, in a regional study in South Africa, was 12.3 per 100 000 population. The study was a retrospective analysis of medical files over a six-year period where 188 cases were included in their analysis. The trend seems lower compared with Joseph et al. (2015), who found a higher incidence rate for a shorter study period. This could be due to cases being missed due to the retrospective design employed by Pefile et al. (2018). The methodologies were different and caution should be taken with comparison. More research is necessary to establish this trend within South Africa, using the standardised method of documenting and reporting incidence rates.

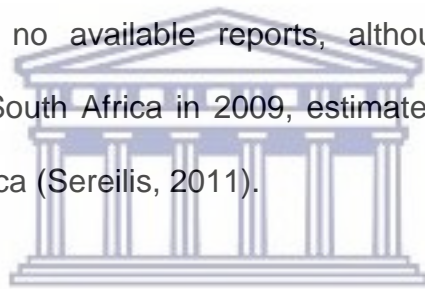
There was numerous incidence data available for TSCI globally and even locally for this review. While challenges were noted by several older studies in obtaining incidence data in Africa, recent reviews found several recent incidence studies in Africa. The importance in understanding incidence levels on the occurrence of TSCI,

in any given population, is linked to the prevention strategies employable to curtail its occurrence. The current study was interested more in incidence rates than the prevalence rates, as the main aim of the study was to ascertain the need for CVD prevention programmes in the TSCI population in a regional area in South Africa. The majority of data reviewed were retrospective in nature with a few prospective and cross sectional studies coming from developing countries in Africa. Of concern was the high incidence rate found in South Africa further highlighting the need to understand this phenomenon and identify the factors impacting these high numbers in order to suggest TSCI prevention strategies for the local context and begin to understand the health challenges they face as they age.

Prevalence

Sekhon and Fehlings (2001, p. S3) defined prevalence in acute SCI as “all persons with a SCI in a specified population at a particular point in time”. The WHO (2013) highlighted further that prevalence was influenced by risk and duration of a condition, and that the latter was determined by recovery or death. They purported that regular collection of demographic data could highlight important patterns and trends in the lived experience of the SCI population. As a result of varying standards of reporting SCI globally, Cripps et al. (2011) averred, more than five years ago, that insufficient data existed to derive a global prevalence for SCI. The range of reported global prevalence identified from their literature review was between 236 and 1009 per million. Wyndaele and Wyndaele (2006) found two studies and three reports on the prevalence of SCI since 1995. Different methodological approaches used to derive prevalence made it difficult to compare figures globally. This was highlighted with two of the studies they identified from Australia and Finland. The Australian study used

the relationship of prevalence (P) to the multiplicative product of disease incidence (I) and disease duration (D): $P = I \times D$ (O'Connor, 2005). The Finnish study used cases identified using the SCI registers (Dahlberg et al., 2005). Their respective prevalence rates were 681 and 280 per million inhabitants. The three reports that Wyndaele and Wyndaele (2006) identified were the Stockholm Spinal Cord Injury Study (SSCIS) in Sweden, The National Centre for Injury Prevention and Control (NCIPC) in the USA and The National Spinal Cord Injury Statistical Centre (NSCISC), also in the USA. Their respective prevalence rates estimations were 223, 700 and 755 per million inhabitants. All of these studies on prevalence were from developed countries. There was no published data for the rest of Europe, Asia, South America, and Africa. In South Africa, there were no available reports, although an estimation by the QuadPara Association of South Africa in 2009, estimated that 50 000 people were living with SCI in South Africa (Sereilis, 2011).



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The sparse reporting on prevalence estimations worldwide highlights the need for further investigation and standardisation. While the lack of reporting is evident in both developed and developing countries' research findings, the importance of understanding the prevalence of TSCI is crucial to identify historical trends and peak periods or places, and to determine whether specific regional prevalence rates are on the incline or decline. Wyndale and Wyndale (2006) reported that the lack of prevalence data, globally and locally, was surprising, given that knowledge of SCI prevalence is considered important given the impact of SCI on healthcare systems. They further noted that differing methodologies used to derive prevalence statistics as one of the reasons for poor global comparison. This information is even more important in a developing country like South Africa where resources are sparse and

need to be targeted. More research is needed to ascertain prevalence rates and the impact of TSCI on the healthcare system locally.

2.2.3 Etiology

The International Spinal Cord Injury Core Data Set (ISCOC) is a standardised data collection and reporting tool for SCI, which reports a minimal amount of information necessary to evaluate and compare results of published studies (DeVivo et al., 2006). Some of these variables include age, gender, and injury etiology. According to the standardised tool, etiology of injuries are classified as a result of sports, assault, transport, fall, other traumatic cause, non-traumatic spinal cord dysfunction or unspecified or unknown.

The WHO (2013) summarised international etiological data, across the WHO regions, on TSCI (see Figure 2.2 below). In summary transportation, falls and violence were identified as the main causes of TSCI globally and is unpacked in more detail later in the following sections. While Figure 2.2 summarises the regional variations in the distribution of causes and context of TSCI, it does not sufficiently portray country-specific differences for this group of injuries.

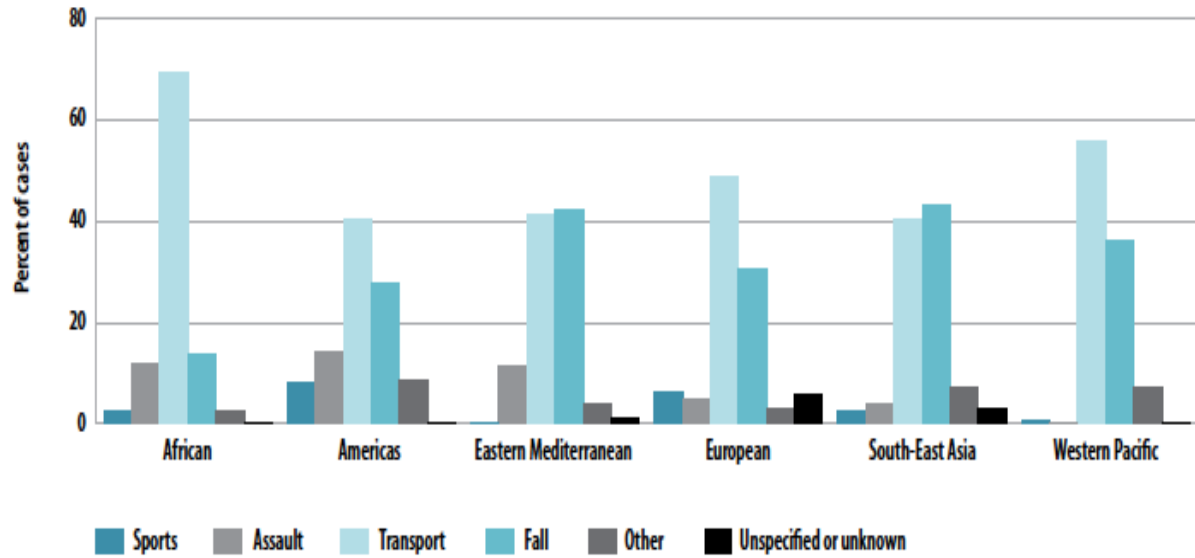


Figure 2.2 Distribution of causes of TSCI by WHO Region (Source: WHO, 2013, p. 19)

The main causation of TSCI was confirmed by the more recent systematic review conducted by Kumar et al. (2018). The studies they identified in their 2018 study for Africa are shown in Table 2.2 and are unpacked in more detail below.



Table 2.2 TSCI studies conducted on the African continent

Reference	Year	Country	Income Level	Population at Risk (N)	Traumatic Spinal Injury Cases (n)	Study Period	Gender Ratio (M/F)	Study Design	Study Scale
Nwadinigwe et al.	2004	Nigeria	Middle		104	1996-2001	5.5	Retrospective	Hospital based
Obalum et al.	2009	Nigeria	Middle		468	1992-2006	2.34	Retrospective	Hospital based
Biluts et al.	2015	Ethiopia	Low		385	2008-2012	5.76	Retrospective	Hospital based
Joseph et al.	2015	South Africa	Middle	3,860,000	147	2013-2014	5.9 3	Prospective	Population based
Löfvenmark et al.	2015	Botswana	Middle	2,000,000	52	2011-2013	2.5	Prospective	Hospital based
Sothmann et al.	2015	South Africa	Middle		2042	2003-2014	5.25	Retrospective	Hospital based
Ametefe et al.	2016	Ghana	Low		185	2012-2014	3.2	Retrospective	Hospital based

Source: Kumar et al 2018

Transportation

More than five years ago, in a worldwide review of TSCI, Cripps et al. (2011) cited road traffic accidents (RTAs) as the main cause of TSCI for studies from countries like in Taiwan, Vietnam, Thailand, Australia, New Zealand, Poland, Greece, Italy, Turkey, Jordan, Canada and the United States. Almost 50 percent of the TSCI reported cases in Taiwan (49%), USA (48%), Vietnam (47%) and Thailand (47%) were attributed to land transportation. Transportation was also over-represented in Greece and Italy when compared to other western European countries. Researchers identified risk-taking behaviours in young males in Greece as well as destructive driving culture and a need for effective road safety programmes (Divanoglou & Levi, 2009). DeVivo (2012) reported that RTAs were the leading cause of TSCI in the USA and that trends stayed the same over the last four decades. Incorrect use of seat-belts, specifically not using them or them not being available, were cited as the cause of up to 75% of the cases in a region of the USA (Surkin et al., 2000). The WHO (2013) similarly found RTAs as the leading cause of TSCI globally. In the African Region, transport was over represented. In the other WHO regions transport, as a percentage of all cases, ranged from 40% in the South-East Asia Region to 55% in the Western Pacific Region. Currently, this global trend has been seen to be unchanged. In a recent review by Kumar et al. (2018), similar findings were reported citing RTAs as the leading cause of TSCI worldwide (39.5%, SD \pm 16.6%). As more people in developing countries get access to motor vehicles, whether a four-wheel vehicle or two-wheel vehicle, this trend is most likely to persist unless appropriate prevention strategies not introduced to curtail its occurrence. Kumar et al. (2018) further reported that RTAs leading to TSCI were more common in high-income countries (41.6%, SD \pm 16.1%) compared with middle-income countries (40.7%, SD

± 18.4%) and low-income countries (27.2%, SD ± 22.6%). This they attributed to the fact that high-income countries have a significantly higher number of motor vehicles per capita compared to middle-income countries and low-income countries. Incorrect use of seat-belts, specifically not using them or them not being available, were cited as the cause of up to 75% of the cases in a region of the USA (Surkin, et al., 2000).

The WHO (2013) further highlighted RTAs as the main cause of TSCI in Africa, accounting for 70% of the reported cases. A study in Nigeria reported RTAs as the main cause of injury ranging from 57-89% of the reported cases. Olasode, Komolafe, Komolafe, and Olasode (2006) reported that none of the 63 transportation related cases in their Nigeria study were wearing a seat. In Botswana (Löfvenmark et al., 2015), RTAs were cited as the main cause of TSCI in their prospective hospital-based study at 64% (n=33) and were overrepresented in the age group 31–45 years old. In Tanzania (Moshi et al., 2017) RTAs were cited as the second leading cause of TSCI at 34.3% (n=73). A cautionary note by the authors, however, highlighted inconsistency of hospital recording impacting analysis in their retrospective study. South African studies were mostly consistent with global trends. One hospital-based study in Cape Town reported RTAs as the main cause of TSCI, which accounted for 44.6% of the 2042 cases (Sothmann et al., 2015). This number was much higher in another retrospective study conducted in two hospitals in Kwazulu Natal where RTAs were seen to be the main cause of TCSI in 64% of the cases (Pefile et al, 2018). Joseph et al. (2015) in their population-based prospective study reported RTAs as the second main cause of TSCI, which accounted for 26.1% of the 145 cases. RTAs were further seen as the leading cause of TSCI in the 46–60 and >61 age groups. This was different to the study in Botswana, which cited a lower age for RTAs

individuals. The regional differences seen in South Africa could be as a result of socio-economic variations seen in the populations groups. More research is needed to ascertain the demographics of TSCI population in order to initiate targeted prevention strategies to curtail its occurrence. The finding of RTAs as the main cause of TSCIs seen in South Africa indicates the thrust of prevention strategies. As highlighted by Sothmann et al. (2015), more emphasis should be on prevention campaigns directed at RTAs for all road users, including pedestrians.

Falls

Kumar et al. (2018) recently reported falls as the second leading causes of TSCI worldwide (38.8%, SD \pm 17.7%). They reported that falls were common in both high-income countries and low-income countries; however, many falls in high-income countries tended to occur in the elderly, whereas falls in low-income countries were often work-related. The WHO (2013) noted the same trend, five years ago, with falls being cited as the second leading cause for TSCI globally. More than eight years ago Cripps et al. (2011) cited that Japan had a higher than usual proportion of falls (42%), which was attributed to the extremely aged population with 29.7% of people being aged 60 years old and over. Pakistan and Bangladesh reported some of the highest incident rates of falls with 82% and 63% respectively, particularly off trees and rooftops in Pakistan, and trees in Bangladesh. The Fiji Islands also reported a high incidence of falls (39%). DeVivo (2012), more than six years ago reported that falls were the leading cause of TSCI among persons over the age of 60. In the 70s, falls accounted for 16.2% of new TSCI in the United States compared with 21.8% (DeVivo, 2010).

The WHO (2013) cited falls as the second main cause of TSCI in Africa, taking specific note that they were the lowest when compared to other WHO regions. Cripps et al. (2011) reported that most etiological data were from regions in Nigeria (Obalum et al., 2009; Nwadinigwe, Iloabuchi, & Nwabude, 2004; Nwankwo & Katchy, 2003; Solagberu, 2002) and Sierra Leone (Gosselin & Coppotelli, 2005). Almost all of the falls in Nigeria and Sierra Leone were from trees. Collapsed tunnels (cave-in injuries in illegal mining) in Nigeria were second most common (26%). In Tanzania (Moshi et al., 2017) falls were cited as the leading cause of TSCI in their retrospective five-year hospital-based study at 48.8% (n=104). Their study included falls from heights (more than 1 meter above the surface) and other falls (while walking, running or with a load on the head). Falls from heights were more frequently reported among males, 56 (32.6%) as compared to females, 6 (14.6%), whereas other falls (low falls) were more reported among females, 14 (34.1%) as opposed to males, (n=27, 15.7%). This etiological difference with sex was found to be significant ($p = 0.019$). In Botswana (Löfvenmark et al., 2015) falls were cited as the third main cause of TSCI in their prospective hospital based study at 64% (n=33). Previous studies from low- or middle-income countries have shown that fall injuries result predominantly from falling from trees or roofs (Hoque, Grangeon, & Reed, 1999; Levy et al., 1998). In Botswana, falls were mainly work-related, including falls from electrical poles and rooftops during construction work. South African studies were mostly consistent with global trends. One hospital-based study in Cape Town reported falls as the second cause of TSCI, which accounted for 15.5% of all injuries (n=316) (Sothmann et al., 2015). This number was marginally higher in another retrospective study conducted in a hospital-based in Kwazulu Natal where falls were also seen to be the second main cause of TCSI at 20% (n=16) (Pefile et al., 2018).

Joseph et al. (2015) in their population-based prospective study reported that falls were the third leading cause for TSCI and accounted for 11.7% (n=17) of the cases, which was similar to Sothmann et al. (2015) who reported 15.5% number of cases although differences in methodologies need to be noted. The trend seems to be increasing in South Africa when compared to a previous study by Hart and Williams (1994), who reported falls as the cause of TSCI 2.4% (n=15) cases. Falls were also noted to be more common in the older population in recent South African studies. This increase in trend is expected to continue locally and globally with the projected global increase in the aging population (>60 years old) worldwide.

Assault

The WHO (2013) cited violence, including self-harm, as the third main cause of TSCI. The Americas were highlighted as the WHO region with the highest proportion of violence-related TSCI (14%) with Africa coming in a close second (12%). Almost all of the studies reviewed were retrospective in nature and therefore comparable. Interesting to note was that this figure has been reported to be on the decline in the United States from 21% in the 1990s to 12% since 2000 (DeVivo, 2010). More recently Kumar et al. (2018) reported that violence, as a cause for TSCI, was more than double in middle-income countries compared with low-income and high-income countries. They further highlighted that this was caused by only a few countries, particularly in South Africa (Sothmann et al., 2015), Mexico (Rodriguez-Meza, Paredes-Cruz, Grijalva, & Rojano-Mejia, 2016), Brazil (Costacurta, Taricco, Kobaiyashi, & Cristante, 2010), and Botswana (Löfvenmark et al., 2015) that reported a high level of violence-related injuries and that it may not clearly represent middle-income countries as a whole.

With the increase in studies in Africa, higher numbers of violence-related injuries resulting in TSCI have highlighted it as a noteworthy factor in research on the continent. In Tanzania (Moshi et al., 2017) assaults were cited as causing 7.4% (n=16) of TSCI. A cautionary note by the authors, however, highlighted inconsistency of hospital recording impacting analysis in their retrospective study. In Botswana (Löfvenmark et al., 2015), assaults resulted in 16% (n=8) of the TSCI cases in their prospective hospital based study with stabbings (62.5%, n=5) being the main mechanism of violence-related injuries seen. These trends were seen to be similar to global trends. South African studies, however, were seen to be different from global trends. One hospital-based study in Cape Town reported violence-related injuries as the second main cause of TSCI, which accounted for 27.23% (n=556) of cases (Sothmann et al., 2015). This number was much higher compared to another retrospective study conducted in a hospital in Kwazulu Natal where violence-related injuries were seen to cause 9% (n=7) of TSCI (Pefile et al., 2018). This could highlight certain socio-economic concerns specifically noted in the Western Cape compared to Kwazulu Natal, and requires further research to ascertain factors impacting this phenomenon. Some other South African studies highlighted “violence” as the main causation of TSCI (Joseph et al., 2015; Velmahos et al., 1995; Hart & Williams, 1994). Hart and Williams (1994), in their retrospective study, found violence to be the cause 56% of cases reviewed, followed by motor vehicle accidents (25%) and falls from heights (2.4%). Velmahos et al. (1995), in their retrospective study, reported that specific acts of violence accounted for 61% of the cases (gunshot wounds 35%, stab wounds 26%), followed by traffic accidents 30%. Joseph et al. (2015), in their population-based prospective study, more recently confirmed assault as the main causation of TSCI (59.3%, n=86). Sothmann et al.

(2015), however, reported it as the second main causation of TSCI (27.23%, n=556), taking note that the study period was longer than any of the other African studies, but differences in methodologies were noted when compared to Joseph et al. (2015) and Löfvenmark et al. (2015). The main causation of TSCI seen locally highlights the unique problem in South Africa and requires multi-sectorial collaboration and concerted efforts by government departments, communities and individuals to turn the tide on inter-personal violence and reduce and even prevent the occurrence therefore.

Age and Gender

DeVivo (2012) assessed age and gender specific trends in SCI epidemiology. The highest incidence was seen in patients who were in their late teens and early twenties, and generally studies reported a decline in incidents in older age categories. He reported that, while transportation incidence was seen as a significant cause of TSCI across all age groups, the older populations, older than 60 years, seemed to result more from falls (see Figure 2.3 below). The WHO (2013) postulated that age and sex influenced the etiology of TSCI throughout the life cycle. They reported that medical and surgical cases of SCI are most prevalent under the age of one year. Motor vehicle accidents were most common for children and young adults. Violence is seen to cause more TSCI among males in all age groups. Falls become the most common cause after the age of 60. In summation, the WHO (2013) commented that incidence was more likely to occur in young male adults and, interestingly, in the elderly. The elderly were seen to be a low risk category in this study. This is possibly due to the higher incidence rates in younger categories due to violence and motor vehicle accidents. International trends indicate that the highest

incidence of TSCI was seen with younger patients. Kumar et al. (2018) in their worldwide review recently reported an older mean age for TSCI, at 40 years old. They reported that TSCI victims tended to be slightly older in high-income countries compared with low-income countries. This is contrary to the findings seen in Joseph et al.'s (2015) local population-based study, which reported younger individuals to be likely to sustain a TSCI.

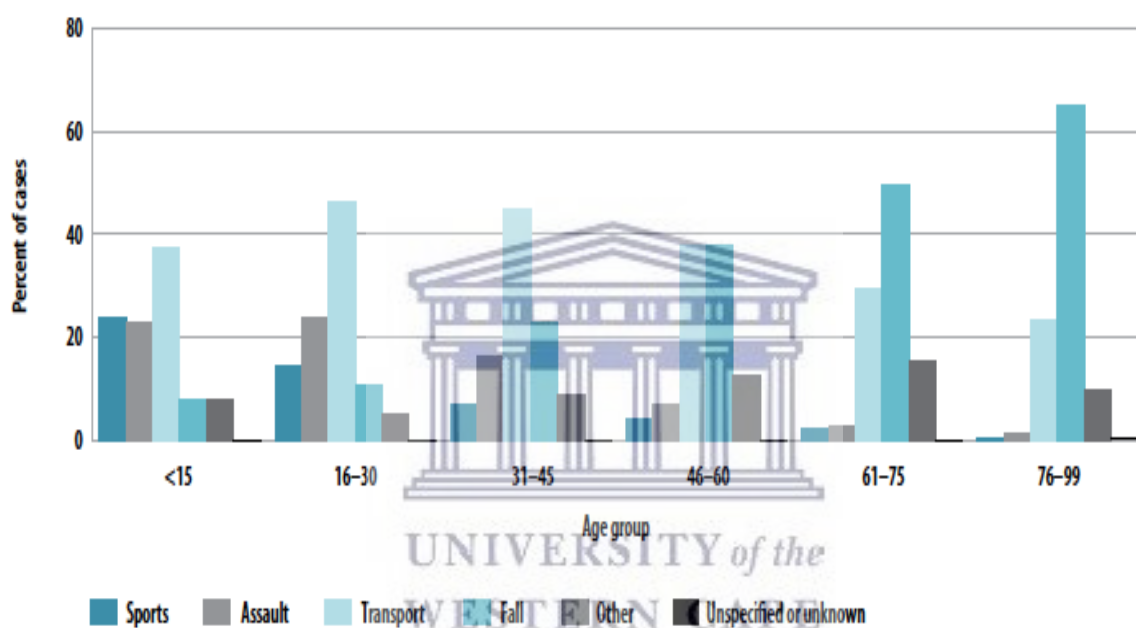


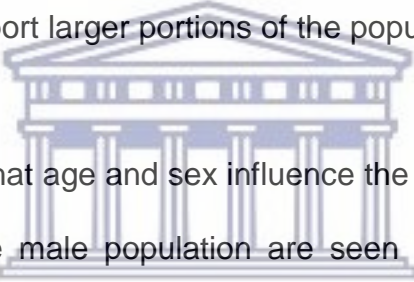
Figure 2.3 Etiology of SCI by age groups (Source: WHO, 2013, p. 21)

Wyndaele and Wyndaele's (2006) worldwide review concluded that most of the patients with SCI were young men, in their thirties and more likely to be paraplegic, complete or incomplete. Studies in Beijing and Tianjin in China reported a mean age of 41.7 years old (Li et al., 2011) and 46 years old (Ning et al., 2011) respectively, which was higher than other international studies. Ning et al. (2011) further reported men to be marginally younger (45.8 years: SD 14.2) compared to women (47.5 years: SD 14.5). Similar mean ages for males and females were seen in Iceland

(Knútsdóttir et al., 2012). An older study by Martins et al., (1998) reported an average age of 50.53 years old in Portugal, which was considerably higher than previous studies which found the average age of SCI to be in their forties (Lan et al., 1993; Garcia-Reneses, Herruzo-Cabrera, & Martinez-Moreno, 1991) and in their thirties (Thurman et al., 1994; Campos da Paz et al., 1992; Dincer et al., 1992; Yarkony et al., 1990). The majority of studies reviewed were retrospective in nature.

Draulans et al. (2011) in their review of SCI in Sub-Saharan Africa found the average age of patients to be higher in the non-traumatic patients compared to TSCI patients. They reported that the average age for TSCI in two Nigerian studies were 37 (Solagberu, 2002) and 30 years old (Olasode et al., 2006), in Senegal it was 36 years (Seye et al., 1993), and Sierra Leone 30 years old (Gosselin & Coppotelli, 2005). South Africa was seen to have the lowest average age (28 years old) (Hart and Williams, 1994) at the time of the study. Age was further grouped in three other TSCI studies, and reported the average age to be between 30 – 40 years old in Nigeria (Obalum et al., 2009), 20 – 40 years old in Zimbabwe (Levy et al., 1998) and 20 – 30 years old in South Africa (Velmahos et al., 1995). This again highlighted a younger cohort in South Africa. Sothmann et al. (2015) reported a mean age of 34 years old for patients who sustained a TSCI in a retrospective hospital-based study in Cape Town, South Africa. The largest age category was 21 - 30 years old (33.5%, n=684) of the total number of patients) followed by the 31 - 40 year age category (25.2%, n=514) and the 41 - 50 year age category (16.6%, n=339). Joseph et al. (2015), in their prospective population-based study, cited similar findings with the age group 18 – 29 years old as the most prevalent (44.8%, n=65,) in a TSCI incidence study in Cape Town, South Africa. A mean age of 33.5 years old (SD=13.8) was

seen. This was lower than the global average. He further reported the over 60 year olds as the least prevalent age category (3.45%, n=5). Very few age and gender specific incidence rates studies have been conducted in Africa. Joseph et al. (2015) further reported significant differences between male and females for age categories 18–29, 30–39 and 40–49. Concerning is the fact that this is seen in the portion of the population that is young and in the prime of their life. Their injury would likely have major social and financial consequences. This age group is seen to be the mean productivity age and would subsequently influence the economic and social structure of the society they lived in. This concern becomes further promulgated in a developing country, like South Africa, where economic resources and social support are limited and need to support larger portions of the population.



The WHO (2013) reported that age and sex influence the etiology of TSCI throughout the life cycle. TSCI in the male population are seen to be more prevalent than women by three to four times (DeVivo, 2010; Wyndaele & Wyndaele, 2006) in studies conducted more than eight years ago. In developed countries, the trends were seen to be consistent. Norway reported a trend of male prevalence with men being 4.2 times more likely to sustain a TSCI between 1992 and 2001 (Hagen et al., 2010). Knútsdóttir et al. (2012) reported slightly lower figures of 72% of male cases but noted that in 2000 – 2004, the female ratio was 37%. Two decades ago, Martins et al. (1998) reported that the male incidence across all age groups was more than 75%, which demonstrated little change in incidence rates. In an Asia Pacific study, Ning et al. (2011) reported a higher male prevalence with an average of 84.9% with a ratio of 5.63:1 males to females. This trend was similarly seen in Estonia during 1997 to 2007 with men accounting for 84.5% (n=503) of the cases compared to woman

(15.5%, n=92)(Sabre et al., 2012).

Developing countries reported higher incidence rates with the proportion of male versus female patients. It was reported to be higher than 66% (male cases) in all 28 developing countries reviewed (Rahimi-Movaghar et al., 2013). The random pooled estimate for male proportion among all countries was 82.8 (95% confidence interval, CI: 80.3–85.2). Zimbabwe had the highest male-to-female ratio (12.4:1) (Levy et al., 1998) and Nigeria had the lowest (2:1) (Olasode, et al. 2006). Joseph et al. (2015) reported a higher incidence of TSCI in males (85.52%, n=124) compared to females (14.48%, n=21) in a regional study in South Africa. Another regional study at the same hospital but over a longer study period reported very similar results with males accounting for 84.0% (n=1 715) of the cases and 16.0% (n=327) females (Sothmann et al., 2015). The male/female ratio was 5.25:1. While local studies mirror many international studies, concerning is the fact that males are more prone to TSCI in a developing context, like South Africa, where they are still seen to be the main breadwinners for households. This further burdens a system that is already stretched. While South Africa has the ability to offer a high level of care, there is a huge demand from poor, uninsured communities (Frielingsdorf & Dunn, 2007). In spite of receiving first-world care post-TSCI many of these patients return to impoverished communities and face huge challenges in terms of survival.

2.3 CARDIOVASCULAR DISEASE

Chronic diseases of lifestyle (CDL), often referred to as non-communicable diseases (NCDs), have long been considered diseases of affluence only affecting ‘developed’ countries, but have been highlighted as a major problem in developing countries

(Pao, Lee, & Grunfeld, 2008; WHO, 2005). CVD is the most common chronic disease around the world (Lloyd-Jones et al., 2010) and accounts for 31% of all global deaths. Triggering CVD – which manifest primarily as heart attacks and strokes – are risk behaviours such as tobacco use, unhealthy diet, physical inactivity and the harmful use of alcohol. These in turn show up in people as raised blood pressure, elevated blood glucose and overweight and obesity, risks detrimental to good heart health (WHO, 2018). CVD have previously been reported to account for half of the deaths as a result of chronic disease (Centers for Disease Control and Prevention, 2012). It is the leading cause of death in South Africa after HIV/AIDS (Pillay-van Wyk, et al., 2016). This is partly because of rapid urbanisation, which has resulted in an upsurge of coronary heart and coronary artery disease (also known as ischaemic heart disease) and metabolic disorders. Furthermore, CVDs claim more lives than all of the cancers combined (Pillay-van Wyk, et al., 2016), with it being responsible for one in six deaths (17.3%) in South Africa (STATSA, 2015). The major CVD risk factors for able-bodied individuals are hypertension, cigarette smoking, family history of premature CVD, age and low HDL levels (Svircev, 2009; Bauman & Spungen 2008; Myers et al., 2007).

The impact of CVD on the SCI population has received considerable attention in recent years. The literature, however, has been notably mostly from developed countries. Published data from more than ten years ago suggested that CVD has emerged as the leading cause of mortality in chronic SCI (Garshick et al., 2005). The increased CVD risk occurs as a result of a variety of physiological changes related to cardiovascular control that are observed in SCI, and are amplified in individuals with SCI compared with able-bodied individuals, including physical inactivity, dyslipidemia,

blood pressure irregularities, chronic inflammation, and abnormal glycemic control (Lieberman et al., 2011; Krassioukov et al., 2009; Hollis et al., 2009; Bauman & Spungen, 2008). Myers et al. (2007) summarised the major cardiovascular concerns associated with SCI as outlined in Table 2.3.

Table 2.3 Cardiovascular concerns in spinal cord injury

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- Higher prevalence of cardiovascular disease
 - Greater morbidity and mortality from cardiovascular causes
 - Heightened cardiovascular risk factors: low, high-density lipoprotein cholesterol, high total cholesterol and low-density lipoprotein, elevated C-reactive protein, higher prevalence of obesity and greater visceral adipose tissue, increased rate of smoking, physical inactivity, Higher prevalence of insulin resistance, diabetes, and metabolic syndrome
 - Blood pressure abnormalities (orthostatic hypotension, autonomic dysreflexia)
 - Deep vein thrombosis, thromboembolic events
 - Rhythm disturbances Bradyarrhythmias, particularly in the acute phase bradycardia, A-V block, cardiac arrest) Reduced heart rate variability
 - Blunted cardiovascular response to exercise
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Sources: Meyers et al. (2007, pg. 2)

Literature has identified a major contributor to the heightened risk of CVD as the fact that risk factors, including hypertension, hyperlipidemia, obesity, and diabetes, have been shown to be comparatively high among individuals with SCI (Lee et al., 2005; Demirel et al., 2001). DeVivo, Black and Stover (1993) reported more than two decades ago, a high frequency of typically aging-related CVD risks. Furthermore, Cragg et al. (2013) more recently reported that individuals living with SCI have a three-fold greater risk of developing CVD than their able-bodied counterparts.

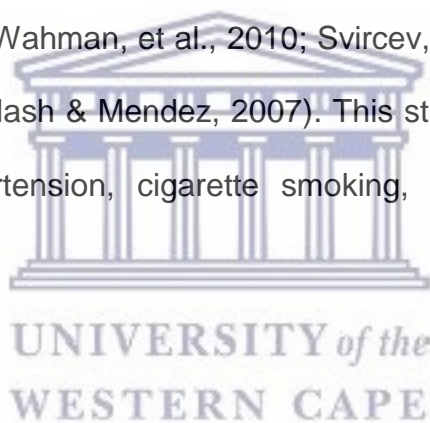
According to Bauman and Spungen (2008), longer lifespan has allowed all-cause CVD to emerge as a serious health concern for individuals with SCI. Sedentary lifestyles (McKinley et al., 2016; Nash, 2005), risk for obesity (Edwards, Bugaresti, & Buchholz, 2008; Weaver et al. 2007), skeletal muscle dysfunction (Dreyer et al., 2008), have all been noted as CVD risks for individuals with SCI. Immobility and muscle atrophy are but some of the consequences post-SCI leading to an increased risk for obesity. More research is, however, required to understand the risk factors and why they might accelerate CVD (Wahman et al., 2010). In spite of the fact that a high prevalence of single CVD risk factors has been reported, there is, as yet, no clear evidence for increased CVD risk after SCI (Wahman et al., 2010; Banerja et al., 2008).



There is very little data available for CVD risk within the TSCI community in South Africa. Given the CVD risk factors associated with aging in the normal population, and the impact that these conditions would have on the SCI population with their moderately normal life expectancy, it becomes imperative to obtain information around the need for population specific prevention strategies to curtail the onset of CVD. This is especially important given that it has been reported to be one of the most prevalent chronic diseases in the able-bodied population (WHO, 2012). This paucity of data within South Africa with regards to CVD risk for TSCI individuals, further highlights the health disadvantages faced within this vulnerable disabled population. Hence this study aimed to understand the challenges faced with regards to the CVD risks faced within the TSCI community and attempts to address this apparent lack of data for the purpose of future development of prevention and intervention strategies.

2.3.1 Risk factors for CVD

Physical inactivity and reduced aerobic fitness, decreased lean body mass and increased adiposity, abnormal glucose homeostasis and increased prevalence of diabetes mellitus (DM), abnormal lipoprotein profiles with elevated low-density lipoprotein, triglycerides and total cholesterol levels, and lower high-density lipoprotein (HDL), abnormal hemostatic and inflammatory markers, and increased activation of the renin-angiotensin-aldosterone system and hypertension are suggested as specific risk factors for CVD in SCI population (Bauman & Spungen 2008; Myers et al., 2007; Warburton, Sproule, Krassioukov, & Eng, 2006). Nearly all risk factors for CVD have been found to be more prevalent in SCI subjects compared with able-bodied subjects (Wahman, et al., 2010; Svircev, 2009; Bauman & Spungen 2008; Myers et al., 2007; Nash & Mendez, 2007). This study looked at specific CVD risk factors namely hypertension, cigarette smoking, alcohol consumption, and physical inactivity.



Hypertension

Hypertension is one of the main risk factors for premature death due to CVD worldwide (Garshick et al., 2005). It has been defined as an elevated blood pressure of 140 mm Hg systolic and/or 90 mm Hg diastolic (World Health Organisation's International Society of Hypertension Writing Group 2003). The prevalence of hypertension in the general population has been shown to increase with age (Vasan et al., 2002) and is influenced by many modifiable lifestyle factors such as high salt intake, physical inactivity, obesity and smoking (Mancia et al., 2013; Kotchen, 2010; Chobanian et al., 2003). Individuals with SCI are not excluded from the development of hypertension (Bauman et al., 2012), since risk factors for hypertension, such as

physical inactivity (Flank et al., 2014; Myers et al., 2007) and obesity (Flank et al., 2014; Wahman et al., 2010; Groah et al., 2002), are common due to a sedentary lifestyle. Hypertension has been suggested as a specific risk factor for CVD in the SCI population (Bauman & Spungen, 2008; Myers et al., 2007; Warburton et al., 2006).

In the general population, there is strong evidence that people with lower lung function measures (in the absence of overt respiratory symptoms or disease) have a higher risk for developing hypertension (Karunanayake, Rennie, Pahwa, Chen, & Dosman, 2012; Schnabel, Nowak, Brasche, Wichmann, & Heinrich, 2011). Decreased lung measures are often a consequence of decreased physical activity often seen in SCI as a result of immobility following injury. While lung function predicts the development of subsequent development of hypertension in able-bodied people (Karunanayake et al., 2012; Schnabel et al., 2011) it is not yet known whether the same association between reduced lung function and future development of hypertension exists in people with SCI.

Bauman et al. (2012) highlighted that blood pressure regulation was altered in people with SCI due to sympathetic nervous system dysfunction. Below the level of the injury there is decentralised vascular control and, depending on lesion level, this may cause cardiovascular disturbances with low resting blood pressure, orthostatic hypotension and autonomic dysreflexia. One of the other common causes of hypertension in the SCI population is caused by renal disease. Significant lability in blood pressure, from extreme hypotension during episodes of orthostatic hypotension to extreme hypertension during episodes of autonomic dysreflexia, is

typical post-SCI and unique features of SCI (Krassioukov, Eng, et al., 2009; Krassioukov, Warburton, et al., 2009). Researchers have speculated that this blood pressure instability could result in vascular injury, and consequently results in a greater risk for arterial disease in individuals with SCI. Adriaansen et al. (2016) recently reported a prevalence of hypertension of almost a quarter (21.5%) in Dutch people with long-term SCI. With such a high prevalence more research is necessary globally and locally to ascertain the risk of individuals with TSCI for developing hypertension given its high propensity to early mortality. Given the paucity of information on the prevalence of hypertension in the SCI population in South Africa, the current study is the first to document the prevalence of CVD risk factors such as hypertension.



Smoking

Worldwide, the number of smokers continues to increase and is estimated to reach 1.7 billion by 2025 (Erhardt, 2009). Smoking is one of six major modifiable risk factors for CVD (Erhardt, 2009). Conversely, CVD is the leading cause of death from smoking (Ezzati, Henley, Lopez, & Thun, 2005; Ezzati, Henley, Thun, & Lopez, 2005; Ezzati & Lopez, 2004). In some regions, including South America, Eastern Europe, and South-East Asia, there were approximately twice as many smoking-attributable deaths from CVD as there were from lung cancer or respiratory diseases during the same period (Ezzati & Lopez, 2004). Most of the risk of acute myocardial infarction (MI) associated with CVD can be explained by nine factors (the INTERHEART study), of these factors, smoking is second only to dyslipidemia as a risk factor for MI (Yusuf et al., 2004). According to the Systemic Coronary Risk Evaluation (SCORE) project, the ten-year fatal cardiovascular risk is approximately

doubled for smokers versus non-smokers (Conroy et al., 2003). It has been further reported that smoking-associated CVD risk appears to be greatest among younger smokers (Erhardt, 2009). Furthermore, while the risk of a heart attack in smokers aged over 60 years is at least twice that of non-smokers, the risk is increased more than fivefold in those less than 50 years of age (Edwards, 2004).

Little research has been done on smoking rates among those with SCI. It has been reported that cigarette smoking is a high-risk behaviour with elevated prevalence at the time of SCI onset (Saunders, Krause, Saladin, & Carpenter, 2015). It has been associated with several secondary health conditions, including pressure ulcers (Krause & Broderick, 2004) and increased pain (Richardson, et al., 2012). In addition, smoking has been directly linked to increased risk of mortality among persons with SCI (Krause & Saunders, 2012; Garshick et al., 2005). Recent research indicated increased smoking rates of persons assessed during in-patient rehabilitation (at the time of SCI) compared with that of the general population (Saunders et al., 2015). The elevated smoking rates were particularly prominent, almost double, for those with a low level of education. Estimates of smoking prevalence among persons with chronic SCI have been shown to be 22.65 to 48% (Saunders et al., 2015; Saunders, Krause, Carpenter, & Saladin, 2014; Haisma et al., 2007). Some of the adverse consequences of smoking after SCI include poor endurance capacity and greater risk of obstructive lung dysfunction (Haisma et al., 2007; Linn et al., 2003), and has also seen pain severity increase following nicotine exposure in persons who have a smoking history (Richardson et al., 2012; Richards et al., 2005). Other health outcomes affected by smoking are an increased risk of recurrent pressure ulcers, hospitalisations, and mortality post injury (Krause, Carter, & Pickelsimer, 2009;

Krause & Saunders, 2009; Garshick et al., 2005; Krause & Broderick, 2004). Comparative mortality rates, associated with cigarette smoking in SCI population, exceed the risks within the general population (Krause & Saunders, 2012; Garshick et al., 2005; Davies & McColl, 2002). Given the paucity of information on the prevalence of smoking history in the SCI population in South Africa, the current study is an attempt to shed some light on some self-reported CVD risk factors such as smoking.

Alcohol consumption

Alcohol is a commonly used drug worldwide (Cahill & Redmond, 2012). Uncertainty exists as to whether alcohol consumption positively or negatively influences many diseases including CVD (Ronksley et al., 2011). Some reports have cited it as positively influencing CVD, with the general consensus currently being that compared with abstinence, frequent moderate consumption of alcohol is associated with the lowest risk for coronary heart disease incidence and mortality (Ronksley et al., 2011; Corrao et al, 2000). On the other hand, other reports cited it as negatively influencing CVD, with excesses or heavy episodic drinking, defined in the USA as consuming five or more drinks in a relatively short time period, being associated with increased CVD and associated mortality (Ruidavets et al., 2010; Mukamal, Maclure, Muller, & Mittleman, 2005). Multiple pathways including genetic and physiological mechanisms play a role in the link between alcohol drinking and CVD risk (Matsumoto et al., 2014). A more recent study in a developed country, namely South Korea, risk-based drinking levels were reported to be more likely to have dose-dependent associations with CVD risk factors in men than in women, and had inverse relationships with 10-year CVD risk in both men and women (Lee, 2018).

The National Institute on Alcohol Abuse and Alcoholism (NIAAA) defines drinking at low risk and at risk for developing alcohol use disorders. Drinking at low risk is defined as ≤ 3 drinks on any single day and ≤ 7 drinks per week for women and ≤ 4 drinks on any single day and ≤ 14 drinks per week for men. Drinking at risk is considered when drinking either more than the recommended daily drinking limits or more than the recommended weekly drinking limits (National Institute of Health, 2016). In the WHO report (2014) South Africa was seen to have a total per capita alcohol consumption of 11 litres in 2010 – 18.4 litres for males and 4.6 litres for females. When only looking at those that drink, per capita consumption for drinkers of both sexes rose to 27.1 litres of pure alcohol, contained in beer, wine, spirits and other alcoholic drinks. According to the WHO's Global Status Report on Alcohol and Health (2014), South Africa was ranked 30th highest of 195 countries for total alcohol consumed per capita (11 litres per person) in 2010. Belarus took the top spot with a per capita consumption of 17.5 litres. The WHO data shows that global average alcohol consumption was 6.3 litres per person in 2010, which translates to 13.5 grammes of pure alcohol per day. In Africa, average alcohol consumption was 6 litres per person. With South Africa being in the upper quarter of the countries reviewed, more targeted research is necessary to understand the prevalence in the SCI.

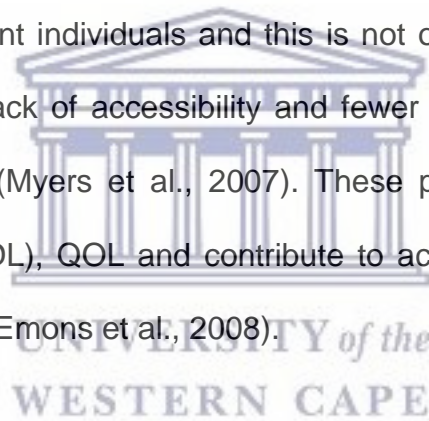
Little research has been done on alcohol abuse among those with SCI. Alcohol abuse has been shown to impact rehabilitation with it being correlated with longer lengths of stays, poor rehabilitation outcomes, decreased life satisfaction, depression, anger, anxiety and increased risk for seizures, pressure ulcers, urinary

tract infections, and re-injury (Krause, Coker, Charlifue, & Whiteneck 1999; McKinley et al., 1999; Heinemann & Hawkins 1995). Estimates of alcohol at the time of injury are reported to be anywhere from 17% to 62% (McKinley, Kolakowsky, et al., 1999; Heinemann, Mamott, & Schnoll 1990). These estimates are even higher for persons with SCI living in the community (Young, Rintala, Rossi, Hart, & Fuhrer, 1995). Heinemann and Hawkins (1995) reported that the prevalence of alcohol use was 90% for 18 to 25 year olds, and 60% for those older than 25 years. Patterns of alcohol use before and after SCI appear to be strongly related. Given the paucity of information on the prevalence of alcohol abuse in the SCI population globally and more specifically in South Africa, the current study is an attempt to shed some light on some self-reported CVD risk factors such as alcohol use.

Physical inactivity


Physical inactivity has been reported among the most frequent risk factors for mortality in the general population (WHO, 2010). According to Martin (2017), physical inactivity levels in the SCI population are alarmingly high. The trend still persists despite previous research. In the SCI population deconditioning is common following the initial injury, and the long-term effects leads to other chronic medical complications (Martin Ginis et al., 2011) such as diabetes mellitus, heart disease, and hypertension. In individuals with SCI, deconditioning is affected by a sedentary lifestyle, which itself can lead to a series of physical and cardiovascular complications (Martin Ginis et al., 2011). Almost five years ago, Vuori, Lavie and Blair (2013) cited that physical activity in the SCI population was necessary to prevent the development of various diseases, including CVD. Similarly, Devillard, Rimaud, Roche, and Calmes (2007) reported more than ten years ago that the lack

of participation in physical activity programmes in the SCI population might lead to reduced self sufficiency and also an increased risk for CVD. According to Devillard et al. (2007), the usual daily activities of individuals with SCI are considered inadequate to maintain fitness. According to Scelza, Kalpakjian, Zemper, and Tate (2005), cardiovascular health is a major concern for those individuals living with a SCI, since heart disease has been found to be one of the major causes leading to death. According to Myers et al. (2007), individuals with a long term SCI are more likely to have morbidity or mortality from cardiovascular disease than from renal and pulmonary conditions, which were the primary causes of mortality in previous decades. The daily energy expenditure within this population is in general lower when compared to ambulant individuals and this is not only due to a lack of motor function, but also due to lack of accessibility and fewer opportunities to partake in regular physical activities (Myers et al., 2007). These problems collectively affect activities of daily living (ADL), QOL and contribute to accelerated aging (Jacobs & Nash, 2004; van den Berg-Emons et al., 2008).



More than five years ago, the CDC (2012) highlighted that regular physical activity was one of the most important things a person could do for their health. The benefits highlighted by them were that it could help with weight control, reduce the risk of CVD, type II diabetes, metabolic syndrome, and some cancers. Several other studies have highlighted specific physiological benefits of being physically active for individuals with SCI. Some of these benefits include enhanced cardiovascular, respiratory and muscle function, as well as improved bone health (Wolfe et al., 2012), decreased pain and depression, (Latimer et al., 2004; Martin Ginis, et al., 2003) increased mobility and enhanced physical independence (Manns & Chad,

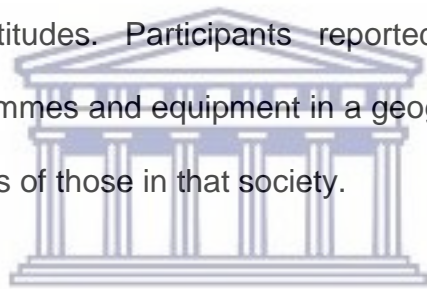
1999) and physical capacity (Jacobs & Nash, 2004). These benefits may have psychological benefits related to enhance quality of life (QOL), or its equivalents, life satisfaction with life after SCI (Tasiemski, Kennedy, Gardner, & Taylor, 2005; Semerjian et al., 2005; Van der Ploeg, van der Beek, van der Woude, & van Mechelen, 2004; Martin Ginis et al., 2003). For the SCI population, regular physical activity can have substantial social benefits, providing a means of establishing new friendships, sharing experiences, developing social support networks, and improving overall functioning (WHO, 2013). Although the benefits of physical activity are evident there remain physiological, psychological and environmental barriers to exercise for individuals with SCI.



The physical activity guidelines for adults with SCI recommend exercise twice weekly consisting of aerobic exercise at a moderate to vigorous intensity and strength training of 8-10 repetitions of each major muscle group (Martin Ginis et al., 2011). The World Health Organisation's previous recommendations on physical activity were to perform aerobic exercises of at least moderate intensity for at least 150 min (2.5 hours) per week (WHO, 2010). Recent research on these physical activity guidelines for adults with SCI, while a good starting point, have been suggested to be an insufficient amount to reduce risks, in particular, for CVD (Totosy de Zepetnek, Pelletier, Hicks, & MacDonald, 2015).

Van den Berg-Emons et al. (2008) found that there was a strong decline in physical activity immediately after discharge from inpatient rehabilitation. This, Schonherr et al. (2005) cited, could be attributed to an increase in time spent on self-care and the extra time needed for coping with inconveniences resulting from incontinence and

mobility problems. According to Tasiemski, Bergstrom, Savic and Gardner, (2000), lower levels of participation in sport recreation was reported to be because of lack of sporting facilities for the disabled, lack of wheelchair access, a dislike of traditional 'disabled' sport, a lack of opportunities for practicing their favourite sport, a fear of further injury and a lack of money and time. Levins, Redenbach and Dyck (2004) in their qualitative study identified barriers to physical activity after SCI. The barriers include (1) 'individual influences', i.e. the issue of self-identity and the struggle to re-establish a new identity consistent with their pre-injury identity, and (2) 'societal influences' which include barriers related to the physical and social environment, of which the most important barriers are inaccessibility of facilities, lack of equipment and negative societal attitudes. Participants reported that the availability of accessible facilities, programmes and equipment in a geographic location are related to the attitudes and priorities of those in that society.



Physical activity of individuals with SCI is often fraught with considerable challenges and is often seen to impede community participation. In South Africa, Mothabeng (2011) highlighted that various factors played a role in community participation and include personal factors, disability related factors and environmental factors. Personal factors included race, level of education, residential area and employment (related to the socio-economic status of the participants). Disability related factors included years living with a SCI, perceived health (re-admission to hospital) and functional ability (level of SCI). Environmental factors included, access around the home and community and transportation. Another relevant theme identified by Mothabeng (2011) was personal needs and includes education, the need to exercise, the need to be independent and the need for employment. Individually and

collectively these factors also play a role in community participation. Mothabeng (2011) also suggested that follow up care was important to ensure that patients do not develop secondary complications after discharge and to ensure maximal participation and community reintegration. According to Jacobs and Nash (2004), the lack of exercise opportunities (environmental barrier) also contributed to a sedentary lifestyle within a SCI population. A study conducted by Maart, Eide, Jelsma, Loeb and Ka Toni (2007), on environmental barriers experienced by people living with disabilities in urban and rural areas in South Africa, found that the majority of the Western Cape sample lives in temporary, informal structures. Furthermore, they reported that 50% of the participants cited barriers to access to public buildings, which had a negative impact on mobility and social integration. According to Maclachlan (2012), inaccessibility of public transport, the lack of recreational and sport facilities, lack of social support structures in the community and inadequate financial resources were the main environmental barriers experienced by individuals with SCI in South Africa. Martin (2017) conducted a study that explored the experiences of community dwelling survivors of SCI in physical activity or exercise within their respective communities. The findings of his study was that most of the participants were aware of the importance of physical activity and that the majority were involved in some or other form of physical activity or exercise. A number of factors influenced the participants approach towards physical activity, mostly external barriers and facilitators many of which have been mentioned in earlier studies above.

Throughout this text physical activity has mainly been used to describe a variety of activities and was at the discretion of the researcher. For the purpose of this

research, the researcher prefers to use the term physical activity as it is related to activities that impact health and wellness, without the explicit goal to improve physical fitness. Physical inactivity is a major concern for individuals with SCI globally and locally and needs more local interrogation as the physical and psychological benefits are considerable. It is also seen to be one of the most cost-effective ways to prevent and manage CVD.

The Constitution of the Republic of South Africa (1996) Act 108 of 1996 and the Bill of Rights (1996) legislates that disabled people in South Africa should be treated as equal citizens with the same access to social and economic opportunities to improve their quality of life. Given the paucity of data available locally for CVD profiles of individuals with TSCI, the current study attempts to assess the need for CVD prevention programmes in the local TSCI population. Understanding the CVD risk of individuals with a SCI in a developing country like South African can assist in reducing its onset through the introduction of specific health promotion and prevention programs. These recommendations might be further developed for the local context if they were to consider the specific facilitators and barriers experienced by individuals to be physically active after SCI. Given the major limited resources for healthcare in a developing context like South Africa, community based wellness programmes might prove to have biggest impact. According to Henderson and Armah (2010), community-based wellness programmes are useful, specifically in areas where health care is limited and poverty is widespread. A community wellness programme is a simple, cost-effective way for municipalities to deliver preventative public health related services.

2.4 HEALTH PROMOTION AND PREVENTION PROGRAMMES FOR INDIVIDUALS WITH TSCI

Meyers, Lee, and Kiratli (2007) suggest that comprehensive CVD risk-factor evaluation should be an integral part of every clinical visit for individuals with SCI. They further suggest that clinicians need to be cognizant of both the high prevalence of CVD risk markers as well as risks that are unique to this population, and they should treat these risks judiciously. They emphasise that regular physical activity should be encouraged, as it has been shown to improve lipid profiles and other risk factors in SCI individuals (Jacobs & Nash, 2004; Washburn & Figoni, 1999; Bauman & Spungen, 1994). Due to physical and environmental limitations experienced by individuals with SCI to participate in physical activity, Meyers et al. (2007) suggest evaluation and follow up by a physical therapist or exercise physiologist to help individuals optimise strategies to improve physical activity participation.

Given the fairly normal life expectancy of individuals who have sustained a TSCI, and their susceptibility to what is considered normal age related conditions, with specific reference to CVD, this study endeavored to assess the risk profile of TSCI individuals one year post-injury and further assess some of the facilitators and barriers related to being physically active once reintegrated in their respective communities. This was attempted to further elucidate the most appropriate CVD prevention programmes within this population. It is understood that changing or modifying a harmful behaviour is difficult for most people. Behaviour is a multidimensional phenomenon and therefore requires properly planned interventions that take into consideration the innumerable psycho-social processes that are involved in behaviour change.

2.4.1 Behaviour change theories

Theories can assist with the conceptualisation of a problem and help provide a basis for understanding and predicting the occurrence of health-related behaviours, behaviour change, and maintenance of change (McNeil, Kreuter, & Subramanian, 2006). The last four decades have seen the development and application of numerous individual-level-behaviour-change theories. This includes theories like the Trans-theoretical Model (TTM) (Prochaska & DiClemente, 2005), Theory of Planned Behaviour (TPB) (Ajzel, 2011), Health Belief Model (HBM) (Rosenstock, 1974), Socio-Ecological Model (SEM) (Sallis, Owen, & Fisher, 2008) and the Social Cognitive Theory (SCT) (Bandura, 2004). One of the main behaviour change theories used in more recent literature is the Socio-Ecological Model (SEM). The SEM considers all of the facilitators and barriers of individuals within a specific context/environment while the other behaviour change theories tended not to focus much on environment. This framework offers a model for the integration of multiple perspectives into the planning of interventions for behaviour as it conceptualises health more broadly than the other theories. This broad approach to thinking of health includes elements of physical, mental, and social well-being. SEM understands health to be affected by the interaction between the individual, the group/community, and the physical, social, and political environments (Sallis et al., 2008; Israel et al., 2005). The model assumes that appropriate changes in the social environment will produce changes in individuals, and that the support of individuals in the population is essential for implementing environmental changes. The model was introduced as a conceptual model in the 1970s, formalised as a theory in the 1980s, and continually revised by Bronfenbrenner. The framework offers a model for the integration of multiple perspectives into the planning of interventions for

behaviour change. Wandersman et al. (1996) concluded that SEM proposes that an individual's behaviour is supported and influenced by numerous nested systems and groups. SEM explains human behaviour in terms of a dynamic, interwoven relationship that exists between the individual and their environment and suggest that the most effective approach leading to healthy behaviours is a combination of efforts at all the levels of the model, namely individual, interpersonal, organisational, community and public policy (Emmons, 2000) (Figure 2.4).

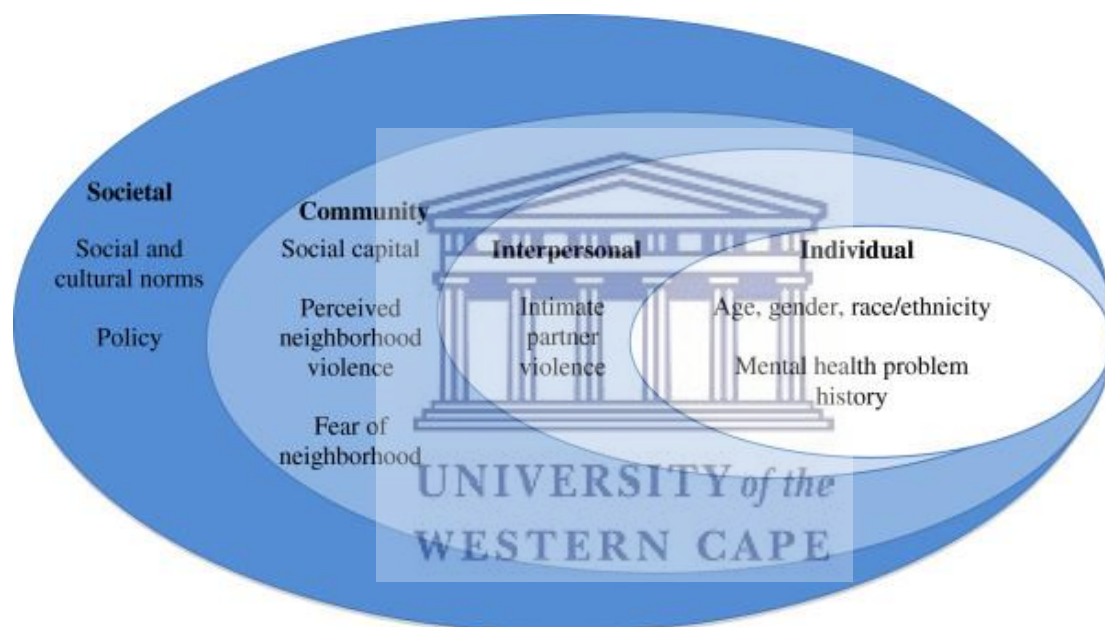


Figure 2.4 The Socio-Ecological Model (SEM)

Bronfenbrenner's Ecological Framework for Human Development applies socio-ecological models to human development. The model outlines five systems, namely the micro-, meso-, exo-, and macro-system, and the chrono-system (Nelson & Prilleltensky, 2010). The micro-system refers to the individual's relationships with family, and close friends, whereas the meso-system refers to the interaction of two or more micro-systems. The exo-system refers to the linkage between the micro-

system and situations or settings that the individual seldom interacts with directly, but that still affect him or her (Nelson & Prilleltensky, 2010). The macro-system implies the broader societal systems and culture that informs social life, education and politics (Nelson & Prilleltensky, 2010). The chrono-system denotes the changes or developments over time and their effects on people (Nelson & Prilleltensky, 2010).

SEM was deemed to be the most appropriate analytical tool for the current study, to assess factors influencing behaviour changes in individuals with TSCI for CVD health promotion and prevention. This theory is better suited for health promotion and prevention, as it looked at health broadly and considered environmental factors while the other behaviour change theories tended not to look at environmental factors. The understanding environment factors is crucial in a developing country like South Africa where there are considerable variations of resources among its citizens living in close proximity to one another. SEM further relates behaviour change to the psycho-social aspects at the individual level (micro-system); interpersonal level (meso- and exo-systems); and the community and societal levels (macro-system). The chrono-system relates to the historical context of the healthcare system, the healthcare systems relationship with the community, in this case the TSCI community, and the South African history.

2.5 THEORETICAL FRAMEWORK OF THE STUDY

The functional outcomes of individuals with TSCI are imperative in understanding the reintegration of these individuals back into their respective communities. Several outcome measures have been used to assess this, namely the Modified Bartel Index (MBI), the Quadraplegia Index (QIF), the Functional Independence Measure (FIM)

and the Spinal Cord independence Measure (SCIM). While these tools boast good reliability and validity, they do not take into account the patient's opinion and needs. The International Classification of Function (ICF) exposes this shortcoming defining rehabilitation as all measures necessary to maximise physical and psychological health including social, economic and vocational aspects and that the person and his/her opinion plays an important role in determining outcomes (WHO, 2001).

The WHO (2001) approved the use of the International Classification of Functioning, Disability and Health (ICF) in the fifty-fourth World Health Assembly, to understand and measure key elements of health and disability. It directly contributes to the WHO's efforts to establish a comprehensive population health measurement framework that includes measures of functional domains of health. The ICF, with a focus on human functioning, provides a unified, standard language and framework that facilitates the description of the components of functioning that are impacted by a health condition. It has amalgamated the two constructs of health and disability synthesizing biological, psychological, social and environmental aspects (Kostanjsek, 2011). Kostanjsek (2011) highlighted that while the historical assessment of health and disability was seen separately, the two basic constructs were in fact different manifestations of the same domains of functioning. What makes the ICF even more useful is that we now have a globally agreed-on conceptual framework and common language to document and code functional status information (Kostanjsek, 2011). As a classification, ICF systematically groups different domains for a person in a given health condition in two main parts: 1) Functioning/disability and 2) Contextual factors. The main components of the ICF include impairments of body structure and function; activity limitations; participation restrictions; and environmental factors.

In Figure 2.5 below, the interaction of the ICF components are presented. The health condition (a disease or disorder) may impact functioning at three mutually interacting levels: in relation to the body, at the level of activities, and at the level of participation in society. The way health condition impacts functioning should also be considered within the context of environmental and personal factors. The WHO (2001) has however not fully determined personal factors to include in the ICF.

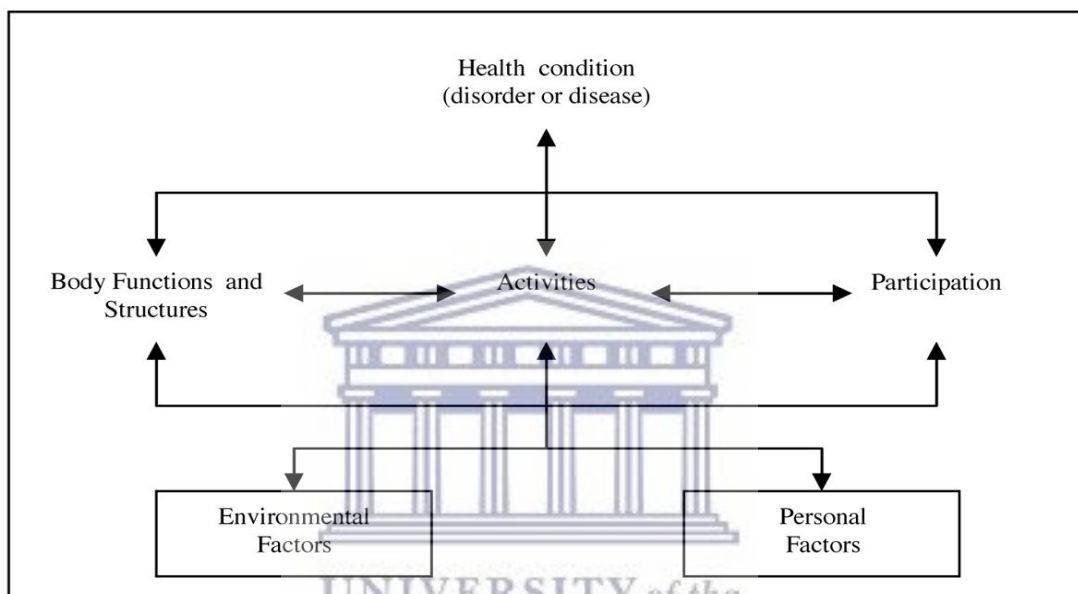


Figure 2.5 Interaction of the components of the ICF (Source: Kostanjsek, 2011, p.3)

The current study attempted to understand both the physical and functional limitations of individuals living with TSCI and how these newfound challenges affected them within their defined context. As the functioning and disability of an individual occurs in a context, the ICF is considered to be the most appropriate tool to ascertain many of the contextual facilitators and barriers of health and the impact on their disability. In the phased approach utilized in the study, the ICF assisted in identify the health condition impacting individuals with a TSCI in phase 1 of the study. In phase 2 and 3 the ICF was used to identify the self-perceived impact that their

health condition had on their body function and system, activities of daily living and their ability to participate meaningfully in their respective communities. Furthermore, it explored the personal and environmental factors impacting individuals once they had been integrated back into their communities. This was deemed appropriate as the researcher wanted to explore the impact of their health condition on their ability to be physically active within their defined context. Identifying these facilitators and barriers assisted in the conceptualisation of the most appropriate prevention and intervention programmes identified in literature for the TSCI population to curtail the onset of CVD within the Cape Metropolitan in South Africa.

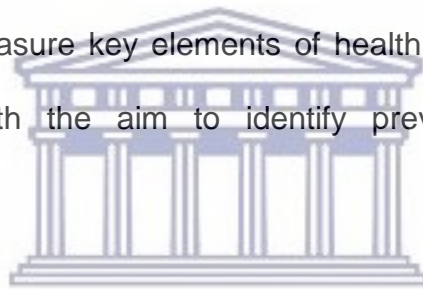
The use of the ICF as the theoretical framework has been argued above highlighting its relevance in addressing the outcomes of this study. It allowed the study to identify facilitators and barriers experienced by individuals in the conceptualisation of a prevention strategy for individuals with TSCI for the development of CVD within the context of a developing country. This framework has been vigorously engaged with in literature and proved to be relevant in the understanding of health and disability and the mitigation of contextually relevant health promotion and prevention.

2.6 SUMMARY OF THE CHAPTER

This chapter reviewed the relevant literature pertaining to the prevalence of TSCI and the factors associated with CVD in this segment of the population. Moreover, several facilitator and barriers to self-management programmes and health promotion interventions, and approaches to delay or reduce the development of CVD complications were also reviewed. The reviewed literature highlighted the paucity of literature related to CVD and TSCI internationally and nationally with few studies

focusing on the South African context. Lastly, relevant theoretical frameworks underpinning epidemiological data collection for SCI and the impact of CDL on individuals with TSCI were also reviewed. The synthesis of the chapter is highlighted below:

- There is an increase in the incidence of TSCI worldwide.
- The prevalence is seen to be more in young males, with men typically being three to four times higher than for females.
- TSCI global incidence range between 10.4 and 83 per million persons.
- The age group mostly implicated in South Africa is 18 – 30 years old.
- The ICF was identified as the conceptual research tool for the study to understand and measure key elements of health and disability for the TSCI population group with the aim to identify prevention strategies for the development of CVD.



In light of the presented reviewed literature, it is evident that clients with TSCI are at greater risk for CVD because of their higher disposition to unhealthy lifestyles and obesity and require more health promotion and self-management empowerment interventions than those living without SCI. Moreover, most health promotion interventions that target clients with CVD are designed for the clients without SCI and implemented in developed countries; hence not addressing the specific socio-economic and cultural needs of the South African SCI population. The study purposed to address these two highlighted gaps.

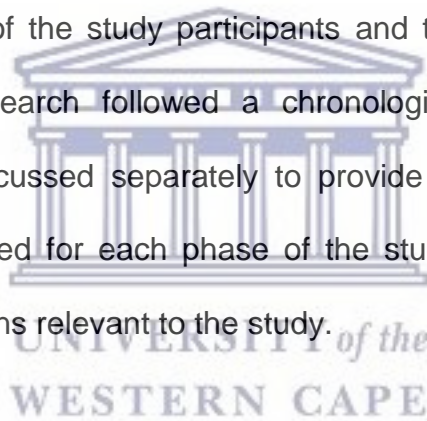
The next chapter will describe the research design and methods used to research the study objectives as outlined in Chapter 1.

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION TO THE CHAPTER

This chapter provides an overview of the methods used in this study. The chapter starts with a description of the research setting, followed by the reasoning behind the choice of research design, namely a population based mixed methods approach. Subsequently, the chapter offers an overview of how participants were recruited, followed by a description of the study participants and the data collected methods utilised. Although the research followed a chronological process, the different research activities are discussed separately to provide a detailed account of the different strategies employed for each phase of the study. The chapter concludes with the ethics considerations relevant to the study.



3.2 RESEARCH QUESTION

The overall goal of the study was to identify the risk for CVD following TSCI in a regional area of the Cape Metropolitan in South Africa. This was done to explore the need to implement CVD prevention programmes for individuals who sustained a TSCI in a regional South African population. The assumptions are that adult clients with TSCI would have:

- A decreased level of physical activity following their community reintegration,
- Limited access to resources essential for their engagement in health promotion activities,

- An increased risk for developing CVD and
- An increased need for tailored prevention strategies for CVD.

3.3 RESEARCH DESIGN

To gain a clear understanding as to whether a need exists for CVD prevention programmes for individuals with a TSCI, both quantitative and qualitative data are needed. The benefits to a mixed methods approach is that the qualitative and quantitative strands are planned and implemented to answer related aspects of the same over-arching research question (Teddlie & Tashakkori, 2009). It has been reported that the combination of quantitative and qualitative research methodology is becoming the preferred method to evaluate public health interventions (Teddlie & Tashakkori, 2009). This is related to the increase in overall strength and comprehensiveness of study findings compared to a single method (Barbour, 2001). According to Creswell, Plano Clark, Gutmann and Hanson (2003), the mixed methods approach, specifically the sequential mixed design utilising both quantitative and qualitative methods for data collection and analysis, produces higher quality data. A quantitative approach was best suited to describe the socio-demographic profile, injury characteristics and CVD risk profile of an inception cohort in the research setting. To gain a deeper understanding of the lived experiences of individuals who sustained a TSCI as it pertained to their ability to be physically active in their respective communities, a qualitative approach was deemed the best methodological approach for this study. In addition, given the complexities of the healthcare system in South Africa, and the varied socio-economic profile of the inhabitants, the mixed methods approach was deemed the most appropriate method to understand the complexities faced by individual with a TSCI as they attempt to

engage in physical activity within their communities. It allowed the researcher to gather quantitative data related to TSCI incidence, and qualitative data to gain an understanding as to how these individuals make meaning of their changed social world following injury as it pertained to their physical activity levels. It was the researcher's position that the social world was not something independent of individual perceptions but that it was created through social interactions of individuals with the world around them. The approach utilised for qualitative design is seen through a constructivist or interpretative lens. This assumes a subjective reality that consists of stories or meanings constructed by the individual and grounded in "natural" settings. The researcher reflected and listened, with the goal of giving voice to respondents' narratives as it related to their lived experiences.

3.4 RESEARCH SETTING

The study was conducted in the City of Cape Town region, which is situated in the Western Province of South Africa. Specifically, it was conducted in the Cape Metropolitan District of the Western Cape, one of the five (5) district municipalities of the City of Cape Town. See Figure 3.1 for the location of this district. The Cape Metropolitan District covers an area of 2,445 square kilometers and has a population of 3 860 830 million people. The predominant population group, based on race, in this district is Coloured (42.4%) and others include Black African (38.6%), White (15.7%) and Indian/Asian (1.3%). Racial terms such as 'Coloured', 'Black African', and 'White' as used in this dissertation refer to the provisions set under the apartheid government. Although the researcher is opposed to racial classification of people and the division it creates, yet in order to contextualise the inequalities that exist in the South African society, it is important to refer to historical labels of racial classification.

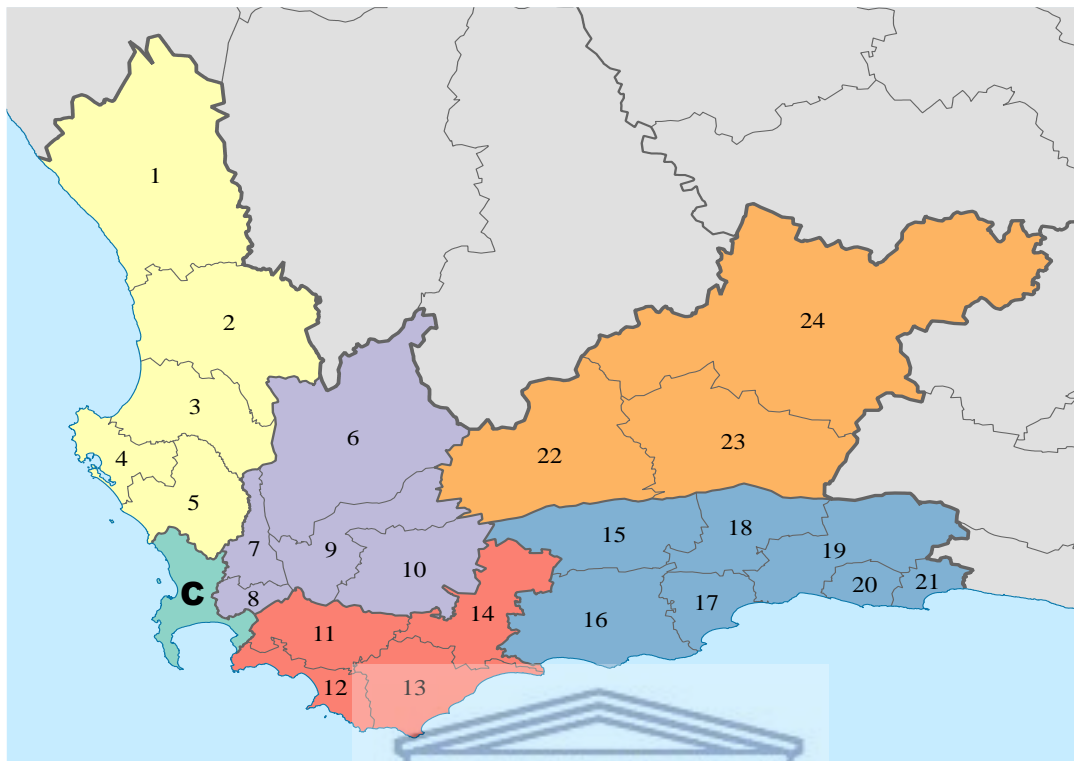


Figure 3.1 Map of the Western Cape District municipalities. 'C' represents the Cape Metropolitan District

3.5 METHODS OF DATA COLLECTION

The study setting, population, sampling, data collection procedures and analysis will be described for each phase of the study.

3.5.1. Phase 1: To describe the profile of individuals with a traumatic spinal cord injury in the Cape Metropolitan Area, South Africa

Setting

This study was part of a larger research project aimed to determine the incidence and mortality of TSCI in the Cape Metropolitan region, South Africa (Joseph et al., 2015).

The larger study included individuals that were admitted to and managed at another non-specialised tertiary institution in the Cape Metropolitan region. The current study was therefore an observational study at the only tertiary facility with a specialized ASCI unit.

To reach the objectives of Phase 1, i.e. to describe the socio-economic profile and injury characteristics of individuals with a TSCI in the Cape Metropolitan Area, data was collected from Groote Schuur Hospital (GSH). GSH is the only tertiary facility, servicing the public sector within the Western Cape, with a specialised acute SCI unit responsible for managing persons with acute SCI. This unit services mostly citizens with government funded healthcare insurance, comprising 75% of the total population in South Africa. The remaining 25% of the population access private healthcare services utilising their private healthcare insurance and were not included in this study. However, due to certain processes and logistical issues patients are often temporarily managed at other institutions within the Western Cape and then referred to GSH ASCI unit. The observation period for Phase 1 was over a one-year period, from 15 September 2013 to 14 September 2014. A one-year period was deemed an appropriate length of time as it allowed the researcher to ascertain sufficient trends of incidence of TSCI within the Cape Metropolitan Area and was further implored given the timeframe and financial constraints put on the researcher.

Study Population and Sampling

Consecutive sampling was used for this phase of the study to collect quantitative data from all patients admitted to GSH ASCI unit. All patients with TSCI admitted to

GSH ASCI unit from 15 September 2013 to 14 September 2014, and were eligible for this study, were included in the study.

All patients with a confirmed first time TSCI, over 18 years and older, residing in the Cape Metropolitan area that consented to participate, were included in the study. The exclusion criteria were patients who declined to participate in the study, a traumatic brain injury, a mental disability and those who had private healthcare.

Methods of data collection

The methods and tools utilised for data collection and analysis are discussed in detail below with further reported reliability and validity of the tools elucidated.

All consenting patients were evaluated and the assessment for level and completeness of lesion was done using the International Spinal Cord Society (ISCoS) basic data set, Core Form and the American Spinal Injury Association Impairment Scale (AIS). Two attending specialist doctors, trained in the use of the data collection tools, completed the ISCoS Data Set, Core Form and ASIA classification score for all admitted patients. In addition, date of birth, gender, date of injury, date of acute admission and discharge (duration of hospital stay), etiology, presence of vertebral fractures and associated injuries, whether spinal surgery was performed, and ventilator-dependence at discharge, and place of discharge details were recorded and kept under surveillance for the first year after the TSCI.

The researcher made contact with GSH ASCI unit twice a week to enquire about the new admissions of individuals with a TSCI. The patient details were recorded and all patients admitted to GSH ASCI unit meeting the inclusion criteria were approached to

participate in the study. The following instruments were used to capture incidence data for Phase 1 of the study:

1. *International Spinal Cord Society (ISCoS) basic data set, Core Form (DeVivo et al., 2006)*

All consenting patients were evaluated and the assessment for level and completeness of lesion was done using the International Spinal Cord Society (ISCoS) basic data set. The data elements include birth date, gender, date and cause of injury, date for acute admission, vertebral injury, associated injury, spinal surgery, ventilator assistance, date and place of discharge from inpatient care, and neurological status (Appendix 9).

2. *American Spinal Cord Injury Association Impairment Scale (AIS) (Kirshblum et al., 2011)*

The ASIA Classification scale was used to collect data regarding the neurological level and the degree of impairment of TSCI. It is a standardised classification system for SCI and has been developed and revised by the American Spinal Cord Injury Association (ASIA) called the American SCI Association Impairment Scale (AIS) (Appendix 10). The AIS consists of two parts, i.e. the Standard Neurological Classification of SCI to establish the neurological level of each subject and the AIS to establish the degree of physical impairment. It is based on clinical examinations of motor and sensory functions. The sensory level is defined as the most caudal segment of the spinal cord with normal sensory function for both pinprick and light touch on both sides of the body. The motor level is defined by the lowest key muscle bilaterally that has a grade of at least 3, provided the key muscles represented by segments above that level are judged to be normal (grade 5). Neurologic level of injury is then defined as the most caudal segment of the spinal cord with both normal

sensory and motor function, that is, the most cranial of the sensory and motor levels. The AIS is described as either grade A, B, C, D, or E in accordance with the International Standards for Neurological Classification:

- C1–C8 ASIA A (complete tetraplegia);
- C1–C8 ASIA B, C, or D (incomplete tetraplegia);
- T1–S5 ASIA A (complete paraplegia);
- T1–S5 ASIA B, C, or D (incomplete paraplegia).

Over the last decade, the International Spinal Cord Injury Data Sets project developed a number of International Spinal Cord Injury Data Sets (ISCIDS) that can be used to collect standardised information on patients with SCI. The International Spinal Cord Society (ISCoS) basic data set, Core Form, and the ASIA Impairment Scale (AIS) outlined above have been extensively used and have subsequently reported to yield valid and reliable scores. Validity of the ISCoS data set has been established by a laborious process of discussion and documentation of each measure at meetings, conferences and the input from national and international societies and organisations as reported by DeVivo et al. (2006). Marino and colleagues (2008) report on the reliability and repeatability of the motor and sensory examination of the International Standards for Classification of Spinal Cord Injury (SCI) in trained examiners. Related studies on the reliability of the motor and sensory examination have tended to focus on inter-rater reliability rather than on responsiveness or repeatability. High reliability of the Light Touch and Pin Prick and motor examinations have been reported by Cohen and Bartko (1994) with inter-rater reliability values ranging from 0.96 to 0.98 and intra-rater reliability values between 0.98 to 0.99 for the 3 scales. Important to note here is that reliability is generally

determined using a correlation coefficient, such as the Pearson, Spearman, Cronbach or intraclass correlation coefficient (ICC) reflecting the degree to which the scale is able to distinguish persons with different levels of the attribute being measured. The ICC is preferred because it does detect systematic differences and does not over-estimate reliability. Inter-rater reliability values for sensory and motor scores were very good to excellent in most cases, except for pin prick in incomplete patients. For all patients, the ICC for total motor score was 0.98; for light touch 0.96, and for pin prick 0.89. The findings for Marino et al's (2008) study indicate that inter-rater reliability of the summed scores for light touch can be high in trained examiners. In this study, the scores generally exceeded recommended reliability values; more training may be required to achieve acceptable reliability of pin prick scores. Furthermore, formal training in the administration of the AIS standards has been shown to improve the accuracy of the examiner's classification (Schuld et al., 2013). The AIS has been validated for injury classification (Graves, Frankiewicz & Donovan, 2006). In addition, construct validity of the ASIA motor score as a measure of recovery following SCI and as an outcome measure for clinical trials is greater when upper and lower extremity motor scales are scored independently and not summated together (Graves et al., 2006).

In the present study, two doctors were used to collect the AIS data from patients at GSH ASCI unit and were experienced in the classification of SCI patients. Only an English version of the ISCoS data collection tool was used by the research assistant (a trained physiotherapist), and no translation of the instruments was deemed necessary for the current study. In the event where a patient spoke Afrikaans or isiXhosa, an interpreter was used to collect the baseline data for this phase of the

study. Furthermore, data was recorded using the doctor's notes on patients to ascertain certain baseline quantitative data such as classification of injury, management of injury, ASIA classification and demographic information.

Data analysis

Complete data were captured on a spreadsheet using the Microsoft Excel (2011) programme in preparation for analysis. Question responses were coded into meaningful variables and analysed with the Statistical Package for the Social Science (SPSS) (version 25). Descriptive statistics were employed to summarise the baseline demographic data of individuals who sustained a TSCI during the study period. Continuous variables such as age, time since injury and length of stay in hospital were expressed in terms as means and standard deviations. Categorical variables such as gender, employment and level of education were expressed as frequencies and percentages. Graphs, pie charts and tables were used to present results. Statistical mean differences between ASIA sub categories were calculated using independent Student T-tests. The Pearson Chi-Square test was used to assess cross-tabulated associations between nominal variables in the study. For all statistical comparisons, p-values, rounded to two decimal points, were quoted to indicate level of significance. Statistical significance was reported when an associated p-value of ≤ 0.05 was obtained.

3.5.2. Phase 2: To determine the cardiovascular disease risk profile of individuals who sustained a traumatic spinal cord injury in the Cape Metropolitan Area, South Africa

Population and sampling

The participants included in Phase 2 of this study constituted the study population.

The study sample consisted of all consenting individuals with a TSCI who agreed to be contacted one year after sustaining a TSCI. A one-year period post TSCI was chosen because at this stage the primary rehabilitation is typically over and the neurological functional outcomes are likely to be stabilised.

Methods of data collection

The methods and tool utilised for data collection and analysis are discussed in detail below with further reported reliability and validity of the tools elucidated.

Data for this phase of the study was collected by means of a questionnaire described below:

1. WHO STEPwise approach to Surveillance (STEPS)

Since its inception in 2000, the STEPS approach has advocated that small amounts of good quality data are more valuable than large amounts of poor quality data (Armstrong & Bonita, 2003). The STEPS approach supports monitoring a few modifiable NCD risk factors, which reflect a large part of the future NCD burden. The STEPS approach is a standardised method of collecting, analysing and disseminating data in WHO member countries for non-communicable diseases. The instrument requests information for demographic information such as gender, age, highest educational level, marital status and socio-economic status. Behavioural measurements include tobacco use, alcohol consumption, diet and physical activity. In addition, information regarding history of raised blood pressure, diabetes and lipid disorders is requested. The STEPwise instrument has been used successfully in numerous continents including Africa (Riley et al., 2016) and was used in the current

study to collect data on behavioural measurements regarding tobacco use, alcohol consumptions, and raised blood pressure.

The WHO STEPS instrument is grounded in the concept that surveillance systems require standardised data collection, but also sufficient flexibility in order to be appropriate in a variety of country situations and settings (Armstrong & Bonita, 2003). The WHO STEPS instrument covers three different levels or 'steps' of risk factor assessment (Riley et al., 2016). In Step 1 information on demographics and behavioural risk factors is collected through a questionnaire. The current study was only interested in collecting data around tobacco use, alcohol consumption, and history of raised blood pressure. A research assistant collected information on behavioural risk factors through face-to-face interviews with patient from the original TSCI cohort and captured the information on the English version of the questionnaire (Appendix 11). In Step 2 physical measurements are taken, of which the current study only recorded the blood pressure readings of patients. A research assistant recorded this on three separate occasions while patients were in GSH following their TSCI. In Step 3 biochemical measurements are taken which include fasting blood glucose and total cholesterol levels. This was not part of the current study and therefore not recorded. The current study operated at the second level (Step) and incorporated some of the Core modules of the questionnaire based Step 1 and physical measure of Step 2. Within each Step, the "core" items have been identified as those, which will enable the collection of the most essential information on the risk factor being assessed.

The STEPS instrument outlined above has been used internationally (WHO, 2011; WHO, 2005) and in several studies in Africa (Maimela et al., 2016; Msyamboza et al., 2011; Dalal, et al., 2011). A recent review by Kroll, Phalkey and Kraas (2015), examined the challenges to the surveillance of non-communicable diseases. While the rising global burden of non-communicable diseases necessitates the institutionalisation of surveillance systems to track trends and evaluate intervention, NCD surveillance capacities vary across high- and low- and middle-income countries. Their findings reveal that NCD surveillance is rather limited in most low- and middle-income countries despite the increasing disease burden and its socioeconomic impact. Major barriers include institutional surveillance capacities and hence data availability. The review suggests that given the complex system requirements, multiple surveillance approaches are necessary to collect comprehensive and reliable information for effective NCD surveillance. Sentinel augmented facility-based surveillance, preferably supported by population-based surveys, can provide improved evidence and help budget scarce resources. In the current study, WHO STEPS data was collected while patients were in hospital following their TSCI.

Complete data was captured on a spreadsheet using the Microsoft Excel (2011) programme in preparation for analysis. Question responses to specific behavioural measurements including tobacco use, alcohol consumption, and information regarding history of raised blood pressure, were coded into meaningful variables and analyzed with the latest version of SPSS (version 25). Summary statistics were reported using means and standard deviations for the scores and frequency tables (and percentages) for the categorical variables. Graphs, pie charts and tables were

used to present results. Descriptive statistics was used to express frequencies in percentages, and to calculate the relevant mean and standard deviation (SD) scores. The Pearson Chi-Square test was computed to ascertain whether there was an association between nominal variables in this particular sample. For all statistical comparisons, p-values, rounded to two decimal points, were quoted to indicate level of significance. Statistical significance was reported when an associated p-value of ≤ 0.05 was obtained.

3.5.3. Phase 3: To explore the experiences of persons with a traumatic spinal cord injury regarding their ability to be physically active once reintegrated back into the community

Setting

A qualitative approach was deemed appropriate to assess the objectives of Phase 3 of the study. The main aim in this phase was to explore the experiences of individuals with TSCI regarding physical activity and how it was affected once reintegrated back into their respective community. A focus group discussion and semi-structured interviews were utilised to explore challenges with physical activity as it pertained to their community reintegration and subsequent CVD risk profile. For the semi-structured interviews, all participants were telephonically approached to set up an initial meeting where the researcher explained the purpose of the study and they were given the opportunity to ask questions. Informed consent was sought at the end of the first meeting and a follow up interview was arranged at a time and place that was convenient for the participants. A collective decision was made to conduct the discussion in a relaxed and convenient setting for the participants; a community hall was used for this purpose.

Population and sampling

Purposive sampling of participants was done after the analysis of Phases 1 and 2 of the study to identify facilitators and barriers to community reintegration and their ability to be physically active once reintegrated back into their respective communities. Selected participants from Phase 2 of the study, residing in the Cape Metropolitan area that consented to participate were included in the semi-structured interviews.

The researcher was cognizant of the fact that the participants from the original cohort might have limited experiences related to their physical activity within their respective communities. This is due to possibly a short lived experience of being a TSCI survivor in their respective communities resulting in a limited understanding of the facilitators and barriers experienced within their communities. Given this possible limitation, the researcher wanted to broaden the perspectives of the qualitative findings of not just participants from the original TSCI cohort but also to assess the experiences of individuals who had been living with a TSCI for a longer period, hence the recruitment of additional participants for the focus group discussion in the study. This was done in order to get a varied and clearer perspective of the lived experiences of TSCI survivors as it pertained to their ability to be physically active once reintegrated back into their respective communities. Leedy and Ormrod (2005) stated that 5-25 individuals for qualitative research are adequate. The aim was identifying a minimum 5 participants for the focus group discussion. Convenient and purposive sampling of additional participants was done for inclusion in the focus group discussion. Participants were selected after consulting with a not-for-profit organisation that kept a registry of individuals who sustained a TSCI and worked

with them to offer support and services after being reintegrated back into their communities. The not-for-profit organisation approached individuals to see if they would be interested to participate in the study after which the researcher was invited to meet with interested individuals to discuss the study and obtain their consent. This was conducted on a specific day at their normal meeting venue. After this meeting, recruitment for the focus group discussion started. Participants had to be over the age of 18 years old, residing in the Cape Metropolitan area, living with a SCI for more than one year, who could speak and comprehend Afrikaans or English and consent to participate in the study. The exclusion criteria were participants who declined to participate in the study, who had a mental disability and who had private healthcare.

Methods of data collection

In order to explore the experiences of individuals with TSCI regarding physical activity and how it was affected following a TSCI, semi-structured interviews were conducted with individuals from the original TSCI cohort, one year after their TSCI. As stated earlier in Chapter 3, participants were purposively selected and approached for participation in the semi-structured interviews. Semi-structured interviews were used to explore the facilitators and barriers participants' encountered with regards to being physically active, CVD education received, and CVD management risk. A facilitator, namely the researcher, acting as the interviewer/observer, facilitated each interview. Participants consented to interviews being conducted in English and/or Afrikaans. Furthermore permission was obtained to record the interviews and it subsequently took approximately 20 minutes to complete. The responses were audiotaped and transcribed.

A focus group discussion was used to explore the facilitators and barriers to being physically active experienced by participants who have had been living with a TSCI for more than one year. While the semi-structured interviews explored CVD risk and physical activity with individuals recently reintegrated back into their communities the researcher wanted to obtain a deeper understanding of how this might change over time, hence inclusion of the focus group discussion with individuals assumed to be fully integrated in their respective communities. Focus group discussions, a commonly employed qualitative data collection method, allow the participants, in interaction with each other, to speak for themselves in the context of their own experience (Bergin, Tally & Hamer, 2003). It has also been identified as a valuable tool in health promotion needs assessment (Tipping, 1998). A facilitator, acting as discussion leader/observer, facilitated the focus group discussion. The participants were informed about the aim of the discussions and that everyone should feel free to participate, as there was no right or wrong answer. The procedure was explained to the participants and each consented participant completed a consent form. The facilitator guided the discussions to permit and encourage participation from everyone in the language used by the majority of the participants namely English and Afrikaans. The group made the decision about language medium. The sessions were concluded when each participant said they could not think of anything else to add. The session lasted about an hour. The focus group discussion was audiotaped and transcribed.

Trustworthiness

Positivist generally often question trustworthiness of qualitative research, perhaps

because their concepts of validity and reliability cannot be addressed in the same way in the naturalistic work (Shenton, 2004). According to Lincoln and Guba (1985), trustworthiness in qualitative data is measured by its credibility, which is determined by the match between assembled realisms of the participants and the data drawn from the participants presented by the researcher. The aforementioned researchers proposed four criteria that should be considered in order to proffer trustworthiness by a qualitative researcher. These criteria are credibility (in preference to internal validity), transferability (in preference to external validity/generalisability), dependability (in preference to reliability) and confirmability (in preference to objectivity). In this study, trustworthiness was enhanced through the strategies detailed below:

1. Credibility (internal validity): During the sessions field notes were compared and discussed (member checking) for their accuracy. Each participant was given a summary of the discussions after the session. Participants were also given time to comment on whether or not they felt the data was interpreted in a manner congruent with their own experiences. Furthermore, the transcribed verbatim draft was reviewed and themes were identified. After the derivation of themes, an independent researcher was asked to read through the transcripts and generated themes. Lists of the researcher and independent researcher's themes were then compared so as to ascertain a final list of themes. Any matters raised by her were incorporated into the written notes. Also, triangulating through data source was employed to enhance credibility of the qualitative data collection by making use of a wide variety of informants. Through triangulation, individual viewpoints and experiences were verified against others and, ultimately, a rich picture of the attitudes, needs or

behaviour of those under scrutiny could be constructed based on the contributions of a range of people (Shenton, 2004).

2. Transferability (external validity): This was enhanced through provision of sufficient contextual information about fieldwork sites (Firestone, 1993) as well as detailed description of backgrounds of the subjects. A detailed description of the methods employed in data collection, data analysis and interpretation was properly described.
3. Dependability (reliability): This was achieved by ensuring that the audit trail consisting of the methodology, original transcripts, data analysis documents, field notes and comments from the member checking were transparent so that any researcher that wanted to adapt the process in his/her own setting could do so.
4. Confirmability: This was achieved through the process of audit trail. Audit trail allows any observer, non-researcher, to trace the course of the research step-by-step via the decisions made and procedures that lead to those decisions. A physiotherapy colleague, who was not involved in the study, was provided with the verbatim transcripts, asked to read through the transcription, discuss it and compare it with researcher's transcription.

Analysis

The analysis of the interviews started with the transcription of information from the audiotape recordings to produce a manuscript. A comparison was then made with the notes taken during the discussions, to verify accuracy. Transcripts were read through several times by the researcher, with emphasis on the emergence from the ideas of themes. Notes were made throughout the reading of the transcripts. Thus,

data was coded in themes, followed by the creation of broad categories of emerging themes, which fit together. Analysis was done by reading through the transcripts again and again, making as many headings as necessary to describe all aspects of the content. In addition, grouping of the themes into broader categories was done in order to reduce the number of themes or small categories; for instance, very similar headings were conflated to come up with one. However, the researcher emphasised searching for categories that had internal convergence and external divergence, which means that the categories had to be internally consistent but distinct from one another (Marshall & Rossman, 1995).

3.5.4. Phase 4: To identify cardiovascular disease prevention programmes for individuals with a traumatic spinal cord injury

To reach the objectives of Phase 4, i.e., to identify cardiovascular disease prevention programmes for individuals with a traumatic spinal cord injury a scoping review was conducted. The scoping review is defined as “a process of mapping the existing literature or evidence base” (Arksey & O’Malley, 2005). The results of the previous three phases were used to inform this phase. The main aim of this scoping review was to identify programmes designed to prevent the onset of CDL for individuals living with a SCI.

Arksey and O’Malley (2005) presented four common reasons for conducting a scoping review: (1) to examine the extent, range and nature of the activity, (2) to determine the value of undertaking full systematic review, (3) to summarise and

disseminate research findings, and (4) to identify research gaps in the existing literature. The main reasons identified for the study are to examine need for implementing a CVD prevention programme in the SCI population locally.

The inclusion and exclusion criteria for this phase of the study are delineated below:

Inclusion criteria

Literature reviewed had to meet the following inclusion criteria:

- The study was focused on SCI individuals only.
- The age of the SCI individuals included in the studies had to be older than 18 years old.
- Publication period of the study was between January 1990 and May 2018.
- Publications were published in English.
- The study assessed prevention strategies utilised for CDL among the SCI population.



Exclusion criteria

- Publications outside the period identified in the inclusion criteria.
- Publications that did not include SCI individuals.
- Non-English publications.

Data collection

The framework proposed by Arksey and O'Malley (2005) has been influential in the conduction of scoping reviews for some time now. The stages of the framework

adopted for conducting a scoping study, described by the aforementioned researches, and used in the study is listed below:

- Stage 1 Identifying the research question
- Stage 2 Identifying relevant studies
- Stage 3 Study selection
- Stage 4 Charting the data
- Stage 5 Collating, summarising and reporting the results.

To identify the relevant studies, appropriate for the scoping review the following keywords were included in the search namely; spinal cord injury, traumatic spinal cord injury, cardiovascular disease prevention, strategies, cardiovascular prevention programs and chronic disease prevention. The search was performed in the following databases: MEDLINE, CINAHL, Academic Search Premier, HEALTH SEARCH: Nursing/Academics Edition, MasterFILE Premier, ERIC, PsycARTICLES and SocINDEX. After reviewing the article titles, some were excluded on the basis of title analysis. Abstracts were reviewed and were selected and sorted according to appropriateness. Full text articles were then sourced from the included abstracts. From the full text articles reviewed, some were excluded leaving the final full text articles, which were included in the scoping review for the final analysis.

3.6 ETHICS

Several ethical considerations were taken into account over the course of this research. Permission and ethical clearance was obtained from Senate Research Grants and Study Leave Committee at the University of the Western Cape (Ethical

clearance number 13/4/27) (Appendix 1). Further ethical clearance was sought from the Western Cape Department of Health (Appendix 2). The study was conducted according to ethical practices pertaining to the study of human subjects, as specified by the Faculty of Community and Health Sciences Research Ethics Committee of UWC and the Western Cape Department of Health.

The following guidelines were followed:

All participants were informed about the over-arching aim of the study, procedures and duration of the study. Written consent was obtained after participants reviewed the consent forms and understood the aims of the study. Consent forms were available in English, Afrikaans and isi-Xhosa versions (Appendix 3, 4, & 5) and participants were informed that their participation in this present research was voluntary and that they could terminate their participation in the research study at any point if they wanted to do so. Participants were ensured of anonymity throughout the research and in subsequent publications. Additional participation information sheets were provided to participants to participate in the qualitative phase of the study. Information sheets were available in English, Afrikaans and isi-Xhosa versions (Appendix 6, 7, & 8). Data files were encrypted to further protect the confidentiality of the information recorded. Recording of interviews and focus groups was also elucidated and no participant in this study objected to the audio recordings. All tapes will be destroyed once the study has been concluded and defended. All information will be kept for a minimum of five years where after it will be destroyed. Furthermore, participants were informed about safekeeping of data, and that the findings would be used in the writing of a dissertation and subsequent scholarly publications.

All participants were informed that there were no immediate health risks and psychological discomfort related to the discussion of the topics under study. However, in the event that a need for counselling was to arise from any discomfort caused by the discussions, participants were informed that arrangements could be made with the university's psychology counseling services. No instances of discomfort or distress stemmed from participation in the present study. The findings of the study will be made available to all the relevant stakeholders.

3.7 SUMMARY OF THE CHAPTER

The chapter started out by presenting a rationale for adopting the research setting. A tertiary hospital in Cape Town South Africa was selected to be the setting for the incidence phase of the study. An overview of some of the key characteristics of the study design utilised was then presented; a mixed methodological approach was used and deemed to be the most suitable methodology for the purpose of this study. An overview of the specific steps in the research phases was then presented, including the procedures that were followed for recruiting and analysis in this study. Lastly, ethical considerations involved in this study brought the chapter to a close.

The next two chapters present the findings related to quantitative analysis of patients with TSCI admitted to GSH ASCI unit during the study period (Chapter 4); the qualitative analysis presented the prevailing themes from the focus group discussions and semi-structured interviews utilised to gain insight into challenges that participants encounter with physical activity and their subsequent CVD risk profile following community reintegration (Chapter 5).

CHAPTER 4

QUANTITATIVE RESULTS

4.1 INTRODUCTION TO THE CHAPTER

This chapter outlines the results of the descriptive data collected from patients who sustained a TSCI within the Cape Metropolitan area in South Africa during the study period. Data was statistically analysed using SPSS and specifically examined the first two objectives of the study. The first two objectives of this study were:

1. To determine the profile of individuals with a TSCI in the Cape Metropolitan Area, in South Africa.
2. To determine the cardiovascular disease risk profile of individuals who sustained a TSCI in the Cape Metropolitan Area, in South Africa.



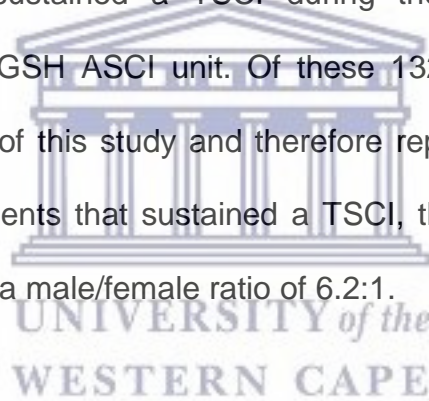
In presenting the results of the study pertinent to these objectives, an overview of the socio-demographic profile of the study patients who sustained a TSCI are presented. The injury characteristics are then presented followed by a presentation of the variables related to their CVD risk profile. The descriptive and statistical results are summarised in tables and graphs to illustrate the findings.

4.2 SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE SAMPLE

This study was part of a larger research project aimed to determine the incidence and mortality of TSCI in The Cape Metropolitan region, in South Africa (Joseph et al., 2015). The research project subsequently looked at TSCI over a one-year period,

commencing on 15 September 2013 and concluded on 14 September 2014, across the Cape Metropolitan area and admitted to the GSH ASCI unit for acute management. The larger research project included individuals that were admitted to and managed at another non-specialised tertiary institution in the Cape Metropolitan region, namely Tybergerg Hospital. The current study was an observational study of the incidence cohort at only one of the hospitals in the Cape Metropolitan area, which is the only specialised acute spinal cord injury (ASCI) unit in the Western Province. It took place over the same period as the larger research study.

Overall, 132 individuals sustained a TSCI during the study period and were subsequently admitted to GSH ASCI unit. Of these 132, 108 consented to being included in all the phases of this study and therefore represents the sample of this study. Among the 108 patients that sustained a TSCI, there were 93 males (86%) and 15 females (14%) with a male/female ratio of 6.2:1.



Patients who sustained a TSCI were predominantly from the Black African race group (52.78%, n=57), followed closely by the Coloured (42.59%, n=46), White (3.7%, n=4) race group and only one case being classified as the “Other” race group (0.93%) (see Table 4.1).

Table 4.1 Socio-demographic characteristics of patients with TSCI (n=108)

Characteristics	Total population (n)	Percentage (%)
Gender		
Male	93	86
Female	15	14
Age categories at time of injury (mean= 33.90)		
18 - 30 years	57	52.78
31 - 45 years	30	27.78
46 - 60 years	14	12.96
61+ years	7	6.48
Race		
Black African	57	52.78
Coloured	46	42.59
White	4	3.7
Other	1	0.93
Marital status		
Never married	81	75
Married/domestic partner	12	11.11
Widower	6	5.56
Separated/divorce	5	5
Cohabiting	4	4.63
Highest educational level		
Less than 12 years	64	59.81
Secondary school	22	20.56
Primary school	12	11.21
Tertiary school	7	6.54
No schooling	1	0.93
Employment status		
Employed	47	43.52
Unemployed	61	56.48



The age of the patients admitted to the GSH specialised ASCI unit ranged between 18 and 69 years old. The mean age was 33.90 years old (SD = 13.55). For females the mean age was 37.66 years old (SD= 17.50), and for males it was 33.29 years old (SD= 12.82) highlighting a lower mean in males compared to females. Age at the time of injury peaked in the third decade age group for both males and females. See Figure 4.1 for the distribution of patients' ages at time of injury.

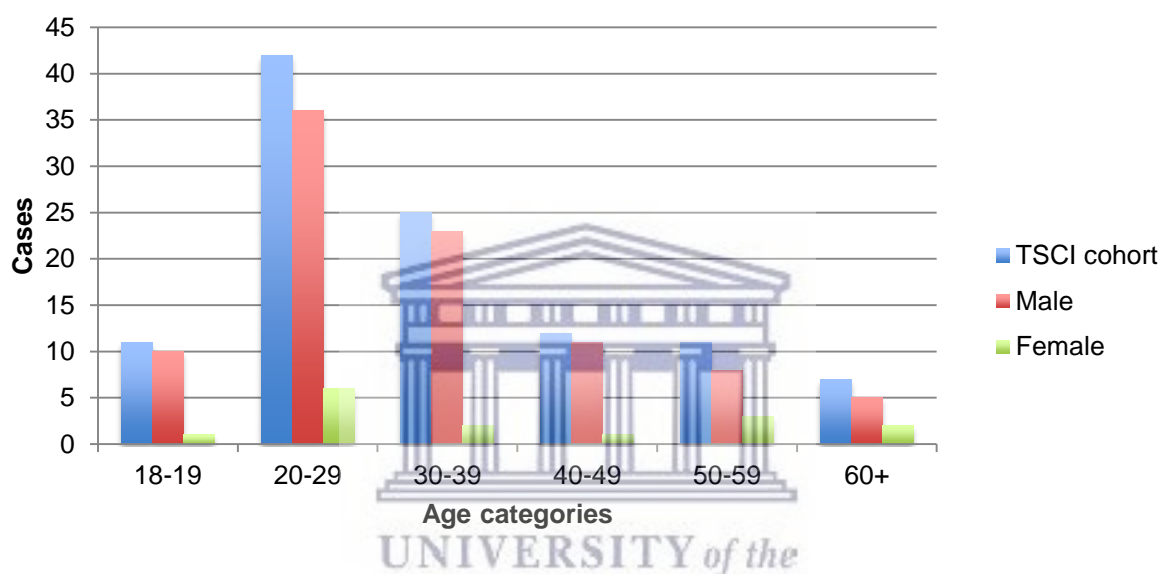


Figure 4.1 Age distributions at time of injury according to gender (n=108)

Furthermore, age at the time of injury according to race group was explored. The most cases for each race group were seen to be in the 20-29 age category for all of the identified groups namely, Black Africans being 40.35% (n=23) of the cohort, followed by Coloured (36.96%, n=17) and White patients (50%, n=2) (see Figure 4.2). No significant association was found between age and gender ($\chi^2=6.581$, $df=3$, $p>0.05$).

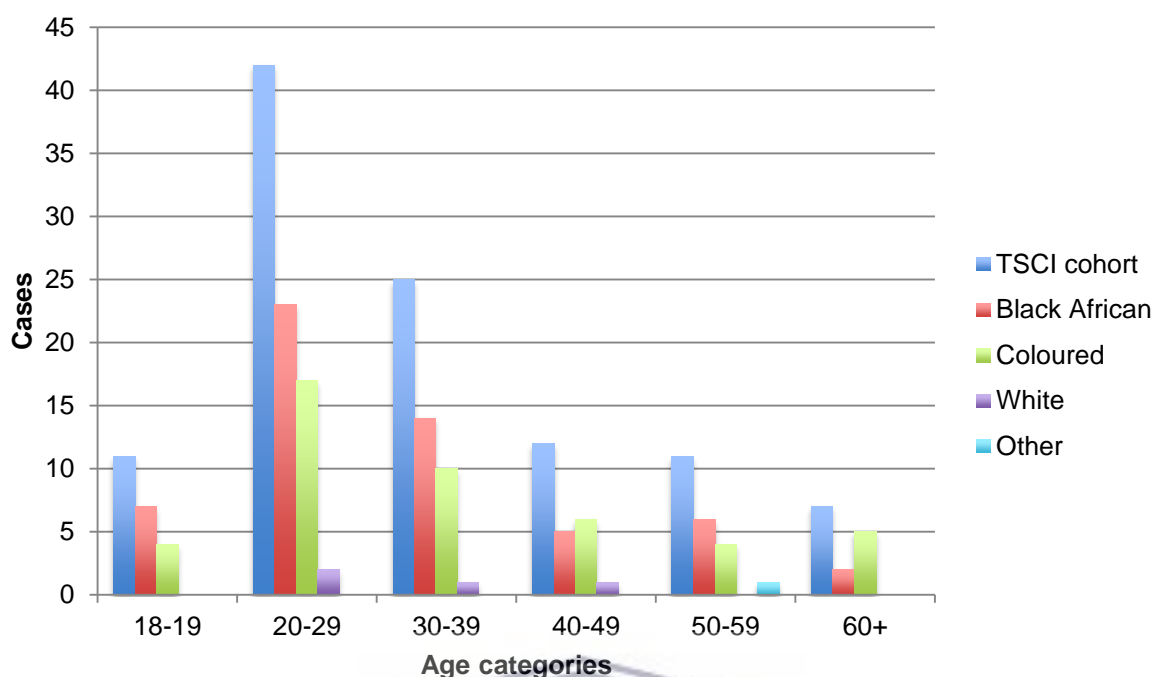


Figure 4.2 Age distributions at time of injury according to race (n=108)

Race compared to gender was also explored. Black African males and females were seen to be the most common race group injured. Coloured males and females were the second most common race group injured.

4.3 INJURY CHARACTERISTICS

Cause

The major causes of TSCI in the study cohort were assaults, road traffic accidents (RTA) and falls (see Figure 4.3). These causes constituted 90.63% of all the TSCI cases. Assault was the most common single cause of injury resulting in TSCI for both males and females constituting 58.33% (n= 63) of the cohort, with a combined mean age of 28.94 years old. The majority of assault cases were seen in males (88.89%, n=56) with a mean age of 29.92 years old (SD=10.8), while females

accounted for 7 (9.39%) of the cases with a lower mean age of 28.29 years old (SD=17.5).

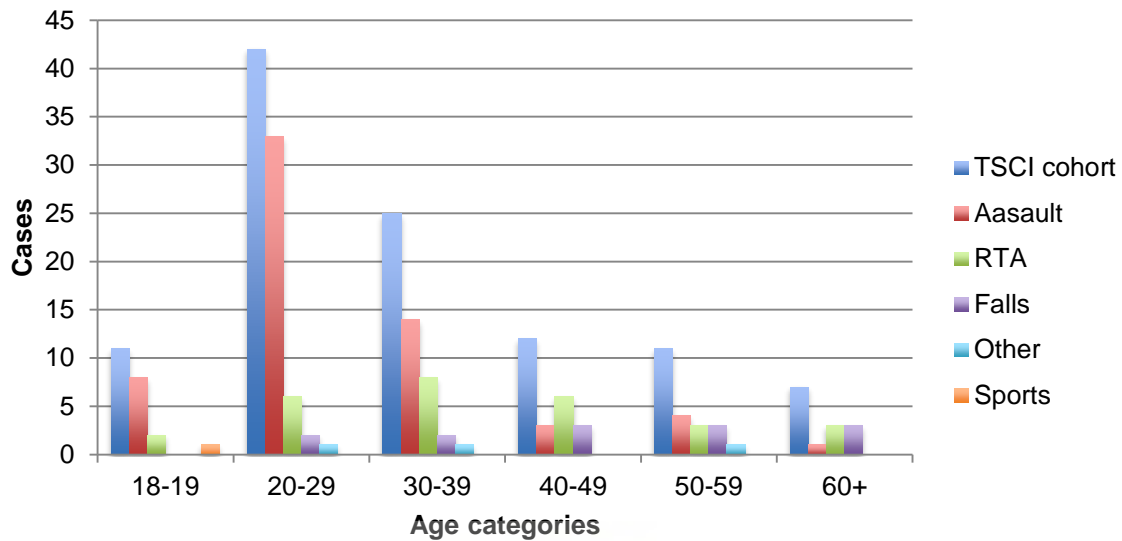


Figure 4.3 Age distributions at time of injury according to cause of TSCI (n=108)

The second main cause of TSCI was RTA (25.93%, n=28) with a mean age of 39.29 years old. Males again accounted for the majority of cases (69.70%, n=23,) with a mean age of 38.43 years old (SD=12.24), while females had 5 cases (30.30%) with a mean age of 43.2 years old (SD=22.06). The causes of TSCI are illustrated in figure 4.4 below.

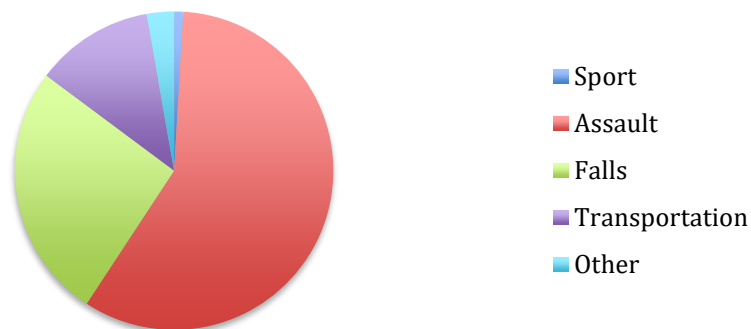


Figure 4.4 Causes of TSCI (n=108)

The age category 20 – 29 years old was significantly more likely to sustain a TSCI due to assault when compared to the other age categories ($\chi^2=28.039$, $p=0.005$, $df=12$) as illustrated in Figure 4.3.

Table 4.2 Injury characteristics (n=108)

Characteristics		
Cause of injury (n; %)		
Assault	63	58.33
RTA	28	25.92
Falls	13	12.04
Other	3	2.78
Sport	1	0.93
Age at time of injury (mean; SD)		
Assault	28.69	13.52
RTA	40.82	13.44
Falls	48.17	13.73
Other	36.33	12.32
Sport	18	-
Level of injury vs age (mean; SD)		
Cervical	37.02	13.69
Thoracic	33.59	13.68
Lumbar	31.9	13.85
Month of injury (n; %)		
March to May (Autumn)	22	20.37
June to August (Winter)	30	27.78
September to November (Spring)	23	21.3
December to February (Summer)	33	30.56

Site of injury (n; %)		
Cervical	55	50.92
Thoracic	43	39.81
Lumbar	10	9.27
AIS classification (n; %)		
ASIA A	42	38.90
ASIA B	9	8.33
ASIA C	14	12.96
ASIA D	43	39.81
Injury Classification (n; %)		
Paraplegia	53	49.10
Tetraplegia	55	50.90
Vertebral Injury (n=107) (n; %)		
Yes	76	70.37
No	32	29.63
Associated injury (n=100) (n; %)		
Yes	62	59.26
No	38	40.74
Surgical management (n=107) (n; %)		
Yes	62	57.94
No	45	42.06
Secondary complications (n=104) (n; %)		
Yes	57	54.81
No	47	45.19
List of secondary complications (n=104) (n; %)		
Pneumonia	27	25.96
Pressure sores	27	25.96
Other	26	25
UTI	19	18.27



Neuropathic pain	7	6.73
DVT	4	3.85

South Africa has four distinct seasons; autumn is defined from March to May, winter is defined from June to August, spring is defined from September to November and summer is defined from December to February. The most TSCI injuries were seen during summer (30.06%, n=33) with both males and females reporting the highest number of cases in this season. Spring was seen to have the least amount of cases (18.52%, n=20).

Location and severity

The cervical part of the spinal cord was the most common site of injury (50.93%, n=55). The amount of injuries found to be at the thoracic and lumbar level were 43 (39.81%) and 10 (9.26%) respectively. No cases were reported in the sacral area (see Figure 4.5). Both male (n=46) and female (n=9) patients sustained more injuries to the cervical area. No significant association was found between level of injury and gender ($\chi^2=1.895$, df=2, p=0.388). The mean ages for males and female were seen to be comparative when looking at the site of injury.

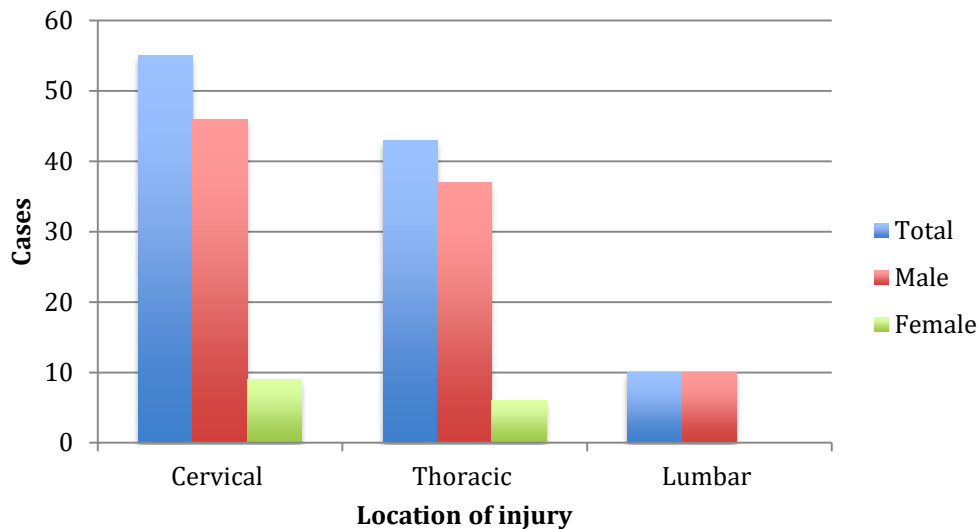


Figure 4.5 Location of injury versus gender (n=108)

The AIS classification scale used to collect data regarding the neurological level and the degree of impairment of TSCI was utilised. ASIA classification A and D were seen to be the most common classification in more than three quarters of the cases (78.70%, n= 85). Forty-two patients (38.89%) were motor-sensory complete (ASIA A) and 43 patients (39.81%) were motor incomplete (ASIA D). Patients with ASIA C classifications constituted the third highest proportion, manifesting in 12.96% (n=14). For males the most common neurological classification was ASIA D with 38 (35.19%) compared to females with ASIA A classification (5.56%, n=6) as seen in Figure 4.6. No significant association was found between AIS classification and age category ($\chi^2=15.0$, df=9, p=0.091) or gender ($\chi^2=4.164$, df=3, p=0.244).

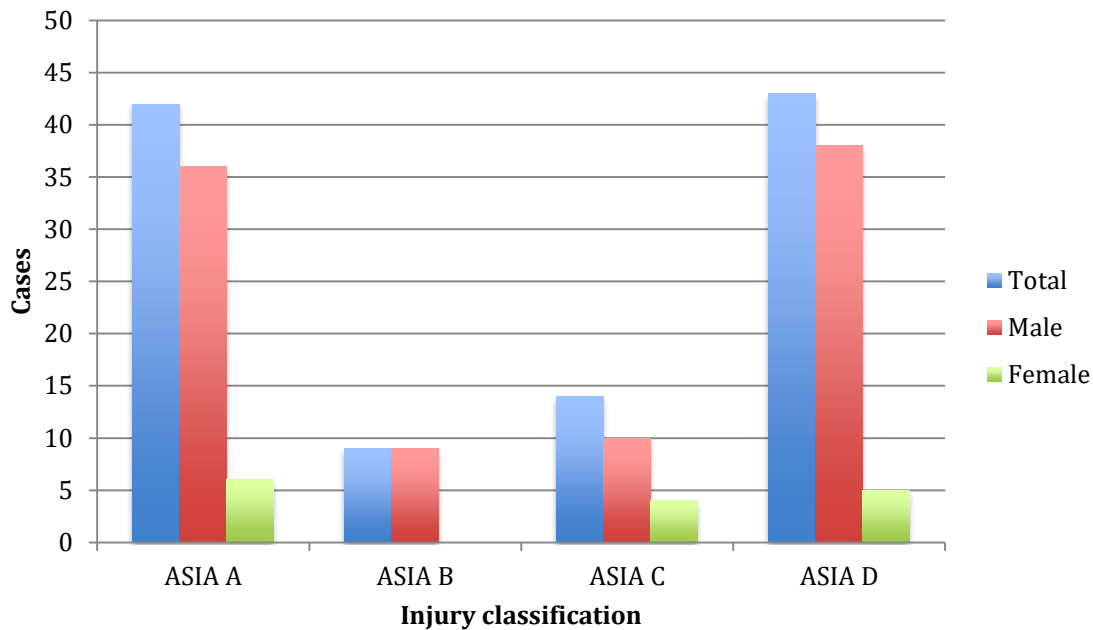


Figure 4.6 Injury classification compared by gender (n=108)

The most common area of the spine injured for ASIA A classified patients was the thoracic area 54.76% (n=23) and for ASIA D classified patients were 46.51% (n=20) in the cervical area. Patients with ASIA C classifications reported the most common area injured as the cervical area (78.57%) (see Figure 4.7). There was a statistical significance when comparing AIS classification and location of injury with a P-value of less than 0.05 ($\chi^2=33.91$, $df=12$, $p=0.001$). This led to a conclusion that the classification of injury had no bearing on the location of the injury sustained and possible the future functional outcome.

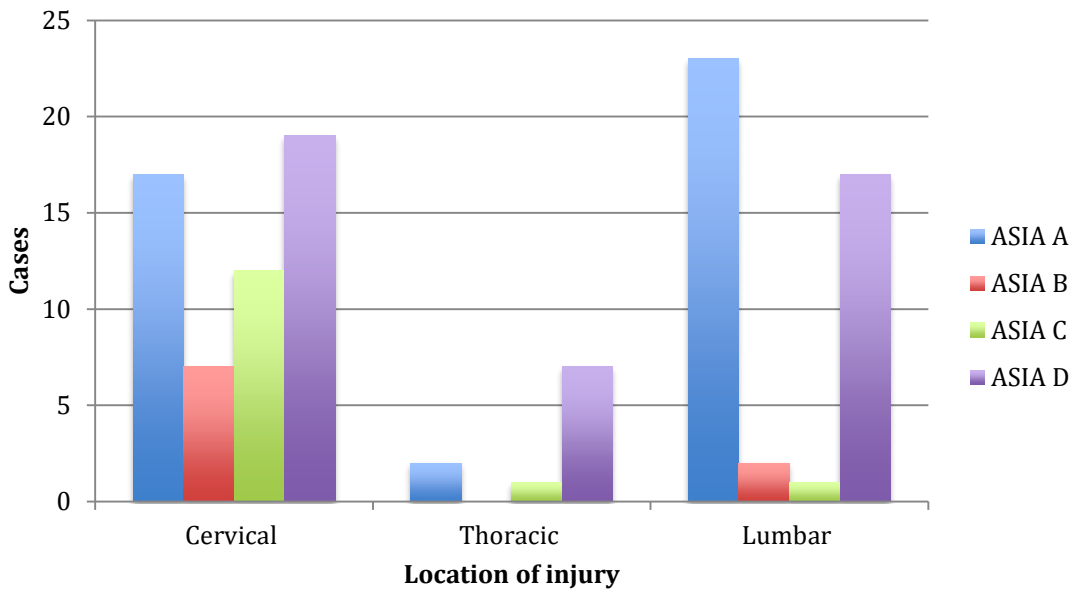


Figure 4.7 Location and severity of injury (n=108)

The distribution of paraplegia and tetraplegia classifications was fairly even with 53 (49.07%) and 55 (50.93) cases reported respectively in the TSCI cohort. Males and females both reported more cases of tetraplegia with 46 (42.59%) and 9 (8.33%) respectively. The severity of injury in the TSCI cohort was seen to have 42 (38.89%) complete motor and sensory deficit cases compared to and 66 (61.11%) incomplete motor and sensory deficit cases. Comparing two categories for injury classification (tetraplegia vs paraplegia) and severity (complete vs incomplete), 23.31% (n=25) with paraplegia had complete injuries compared to those with tetraplegia at 15.74% (n=17%). The association between injury classification and injury severity was not seen to be significant ($P>0.05$).

Management in hospital

Apart from one participant with unknown surgical management, 45 (42%) patients

received conservative management for their TSCI. There were 76 patients (70.37%) from the study cohort who sustained a vertebral fracture following their TSCI. The majority of these cases (81.57%, n=62) received surgical management for stabilisation of the spine. The area of the spine operated on the most was the cervical spine (59.68%, n=37), followed by the thoracic spine (30.65%, n=19). In total, 64 patients (59.26%) presented with associated injuries post-TSCI. Apart from four patients with unknown complications, secondary complications were present in 57 patients (54.81%) with pressure sores and pneumonia being the most prominent (n=27, 25.96%). Other complications were also reported in 26 patients namely, sepsis (n=11, 10.19%), spasticity (n=4, 3.7%), respiratory complications (n=10, 9.26%), and bowel obstruction (n=1, 0.93%). Apart from 8 patients with unknown discharge dates from the GSH ASCI unit, the majority of the TSCI patients were admitted for an average hospital length of stay of 35 days (SD= 34.02) until their hospital discharge with length of stay ranging from 1 day to 159 days as highlighted in Figure 4.8.

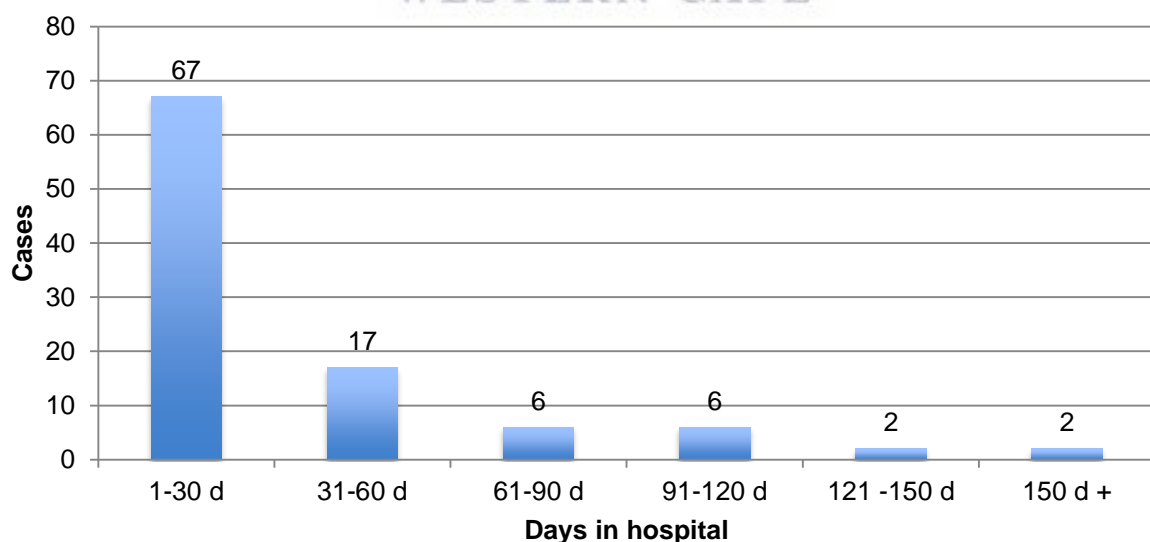


Figure 4.8 Length of stay in GSH ASCI unit for TSCI cohort (n=100)

Of the 108 patients, 104 (96.3%) patients' discharge destinations were recorded with the remaining 4 patients leaving GSH ASCI unit before discharge destination could be established. The majority of the patients went to a specialised rehabilitation facility, namely Western Cape Rehabilitation Centre (65.38%, n=68), with the remaining patients going home (29.81%, n=31) or to another hospital (4.81%, n=5) for further management closer to home (see Figure 4.9).

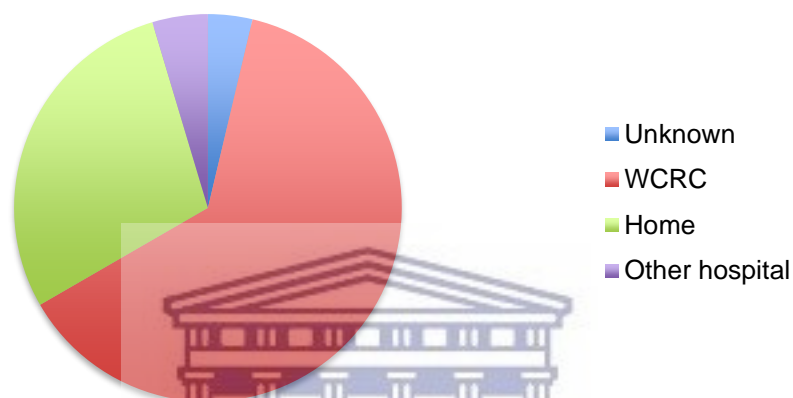


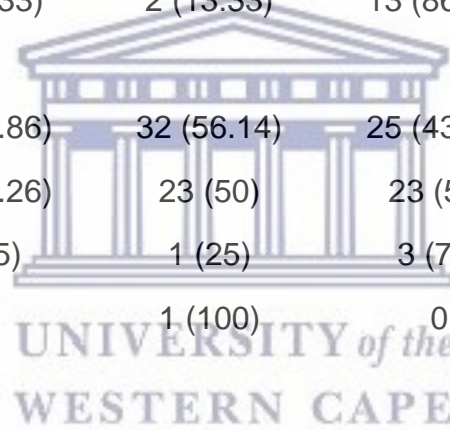
Figure 4.9 Discharge destination (n=104)

4.4 RISK FACTORS FOR CARDIOVASCULAR DISEASE

Some of the main risk factors identified from literature for CVD were smoking, alcohol consumption, and hypertension (Svircev, 2009). Based on this, these variables were used to investigate CVD risk in this study of individuals with acute TSCI at baseline and one year following acute TSCI within the study area. These variables were further deemed appropriate, as they have been shown to be reliable behaviour recall measures. The patients from the TSCI cohort were asked to self-report on various health risk behaviours namely cigarette smoking, alcohol consumption, and history of diagnosis with hypertension as shown in Table 4.3.

Table 4.3 Characteristics of self reported variables (n=108)

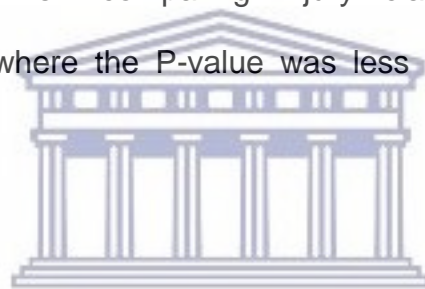
	Smoking		Alcohol		Hypertension diagnosis history	
	Yes	No	Yes	No	Yes	No
Gender n (%)						
Male (n=93)	62 (66.67)	31 (33.33)	55 (59.14)	38 (40.86)	5 (5.38)	88 (94.62)
Female (n=15)	7 (46.67)	8 (53.33)	2 (13.33)	13 (86.67)	1 (6.67)	14 (93.33)
Race n (%)						
Black African (n=57)	32 (56.14)	25 (43.86)	32 (56.14)	25 (43.86)	2 (3.51)	55 (96.49)
Coloured (n=46)	33 (71.74)	13 (28.26)	23 (50)	23 (50)	4 (8.7)	42 (91.3)
White (n=4)	3 (75)	1 (25)	1 (25)	3 (75)	0	4 (100)
Other (n=1)	1 (100)	0	1 (100)	0	0	1 (100)
Age category n (%)						
18 - 30 years (n=57)	31 (54.39)	26 (45.61)	23 (40.35)	34 (59.65)	2 (3.51)	55 (96.49)
31 - 45 years (n=30)	23 (76.66)	7 (23.33)	22 (73.33)	8 (26.67)	1 (3.33)	29 (96.67)
46 - 60 years (14)	10 (71.43)	4 (28.57)	10 (71.43)	4 (28.57)	2 (14.29)	12 (85.71)
61+ years (n=7)	5 (71.43)	2 (28.57)	2 (28.57)	5 (71.43)	1 (14.29)	6 (85.71)



Severity n (%)						
Complete (n=42)	25 (59.52)	17 (40.48)	26 (61.90)	16 (38.10)	1 (2.38)	41 (97.62)
Incomplete (n=66)	44 (66.66)	22 (33.34)	31 (46.97)	35 (53.03)	5 (7.58)	61 (92.42)
Injury classification n (%)						
Paraplegic (n=53)	28 (52.83)	25 (47.17)	28 (52.83)	25 (47.17)	4 (7.55)	49 (92.45)
Tetraplegic (n=55)	41 (74.55)	14 (25.45)	29 (52.73)	26 (47.27)	2 (3.64)	53 (96.36)
ASIA classification n (%)						
ASIA A (n=42)	25 (59.52)	17 (40.48)	26 (61.9)	16 (38.1)	1 (2.38)	41 (97.62)
ASIA B (n=9)	6 (66.67)	3 (33.33)	4 (44.44)	5 (55.56)	0	9 (100)
ASIA C (n=14)	10 (71.43)	4 (28.57)	6 (42.86)	8 (57.14)	0	14 (100)
ASIA D (n=43)	28 (65.12)	15 (34.88)	21 (48.84)	22 (51.16)	5 (11.63)	38 (88.37)
Level of injury n (%)						
Cervical (n=55)	41 (74.55)	14 (25.45)	29 (52.73)	26 (47.27)	2 (3.64)	53 (96.36)
Thoracic (n=43)	22 (51.16)	21 (48.84)	22 (51.16)	21 (48.84)	3 (6.98)	40 (93.02)
Lumbar (n=10)	6 (60)	4 (40)	6 (60)	4 (40)	1 (10)	9 (90)

Smoking

Smoking was seen to be the most common risk factor engaged in by the original study cohort prior to their TSCI. For smoking, 69 patients (63.89%) reported having smoked prior to their TSCI. The 69 patients who smoked had a mean age of 35.42 years old (SD=13.67), with males having a mean age of 35.65 years old (SD=13.38), and female having a mean age of 33.43 years old (SD=15.44). No significant association was found between smoking and age category ($\chi^2=4.872$, $df=3$, $p=0.181$) or gender ($\chi^2=2.239$, $df=1$, $p=0.135$). Black African (46.38%, $n=32$) and Coloured (47.83%, $n=33$) patients had high representation of smoking in this cohort. Significance was seen when comparing injury classification (tetraplegia vs paraplegia) and smoking where the P-value was less than 0.05 ($\chi^2=5.517$, $df=1$, $p=0.019$).



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Alcohol consumption

For alcohol consumption, 57 patients (52.78%) from the original study cohort reported drinking alcohol prior to their TSCI. The 57 patients who consumed alcohol had a mean age of 35.53 years old (SD=13.71), with males having a mean age of 35.98 years old (SD=12.42), and females having a mean age of 30.8 years old (SD=10.28). No significant association was found between alcohol consumption and race group ($\chi^2=2.534$, $df=3$, $p=0.469$), gender ($\chi^2=2.643$, $df=1$, $p=0.104$), injury classification (tetraplegia vs paraplegia) ($\chi^2=2.297$, $df=1$, $p=0.991$), or severity of injury (complete vs incomplete) ($\chi^2=0.000$, $df=1$, $p=0.130$). All race categories were represented with Black African (46.38%, $n=32$) and Coloured (47.83%, $n=33$) patients having a high representation. The age category 18 – 30 years was

significantly more likely to have consumed alcohol prior to their TSCI when compared to the other age categories ($\chi^2=12.218$, $df=3$, $p=0.007$).

Hypertension

Participants reported on their history of hypertension diagnosis prior to sustaining a TSCI. Less than 10% ($n=6$, 5.56%) of the original study cohort reported having been previously diagnosed by a medical practitioner with hypertension. Males accounted for 83.33% ($n=5$) of the individuals diagnosed with hypertension prior to admission compared to females, 16.33% ($n=1$). The mean age for males was 46 years old ($SD=15.73$) and the only female patient was 67 years old. When examining history of hypertension diagnosis according to race, only Black African (20%, $n=2$) and Coloured (80%, $n=4$) patients made up this cohort. There were no significant association found between history of hypertension diagnosis and race group ($\chi^2=1.614$, $df=3$, $p=0.656$), gender ($\chi^2=0.041$, $df=1$, $p=0.840$) age ($\chi^2=3.788$, $df=3$, $p=0.285$), injury classification (tetraplegia vs paraplegia) ($\chi^2=0.787$, $df=1$, $p=0.375$), or severity of injury (complete vs incomplete) ($\chi^2=1.320$, $df=1$, $p=0.251$).

Patients admitted to GSH ASCI unit had several physiological measurements taken during their hospital stay readings such as blood pressure, blood gases, heart rate and body temperature. The study was only interested in blood pressure readings due to its indication of raised blood pressure and the likelihood of hypertension. Three separate readings on different days were taken to establish an average for individual patient's blood pressure. These readings were taken towards the end of their

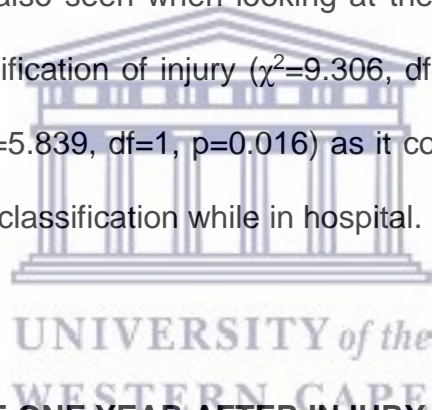
hospital stay as patients were expected to be clinically unstable initially due to the acute trauma. According to The American Heart Foundation (2016), normal blood pressure is less than 120/80mmHg. Furthermore, normal blood pressure readings over 120/80mmHg and up to 139/89mmHg are still considered in the normal range. For the purpose of this study, a variance of more than 10 was used for both systolic and diastolic values to qualify high blood pressure reading. The average blood pressure reading of patients was 123/70 mmHg, which was within the normal range, with a maximum diastolic and systolic reading of 170 and 111 respectively. A total of 40 individuals were seen to be hypertensive with a larger percentage of males (38.71%, n=36) compared to females (26.67%, n=4). When looking at individuals who were classified as being hypertensive, there was no significant association found when compared to gender ($\chi^2=0.803$, df=1, p=0.370) or age ($\chi^2=2.876$, df=3, p=0.411). When looking at hypertension classification according to race groups, statistically significant findings was seen with a P-value of ≤ 0.05 ($\chi^2=11.662$, df=3, p=0.009) with Black African and Coloured patients being more likely to be hypertensive.

Table 4.4 Characteristics of incidence cohort with hypertension according to AHA classification (n=108)

Variable	Hypotensive and normal % (n)	Hypertensive % (n)	P-values
Gender			0.370
Male (n=93)	61.29 (57)	38.71 (36)	
Female (n=15)	73.33 (11)	26.67 (4)	
Race group			0.009*
Black African (n=57)	73.68 (42)	26.32 (15)	
Coloured (n=46)	45.65 (21)	54.35 (25)	
White (n=4)	100 (4)	0	
Other (n=1)	100 (1)	0	
Smoking			0.289
Yes (n=69)	66.67(46)	33.33 (23)	
No (n=39)	56.41 (22)	43.59 (17)	
Alcohol			0.657
Yes (n=57)	64.91 (37)	35.09 (20)	
No (n=51)	60.78 (31)	39.22 (20)	
Injury classification			0.000
Paraplegia (n=53)	45.28 (24)	54.72 (29)	
Tetraplegia (n=55)	80 (44)	20 (11)	
Level of injury			0.001*
Cervical (n=55)	80 (44)	20 (11)	
Thoracic (n=43)	46.51 (20)	53.49 (23)	
Lumbar (n=10)	40 (4)	60 (6)	

ASIA classification			0.025*
ASIA A (n=42)	71.43 (30)	28.57 (12)	
ASIA B (n=9)	88.89(8)	11.11 (1)	
ASIA C (n=14)	71.43 (10)	28.57 (4)	
ASIA D (n=43)	46.51 (20)	53.49 (23)	
Severity			0.146
Complete (n=42)	71.43 (30)	28.57 (12)	
Incomplete (n=66)	57.58 (38)	42.42 (28)	
Previous HPT diagnosis			0.016*
Yes (n=6)	16.67 (1)	83.33 (5)	
No (n=102)	65.69 (67)	34.31 (35)	

Statistical significance was also seen when looking at the level of injury ($\chi^2=11.662$, $df=3$, $p=0.009$), ASIA classification of injury ($\chi^2=9.306$, $df=3$, $p=0.025$) and previous hypertension diagnosis ($\chi^2=5.839$, $df=1$, $p=0.016$) as it compared with the BP mean readings and hypertension classification while in hospital.



4.5 CVD RISK PROFILE ONE YEAR AFTER INJURY

Data was collected assessing changes to CVD risk profile one year after the original TSCI cohort was discharged from GSH ASCI unit. Data collection was difficult to execute and was mired with considerable challenges. From the initial 108 individuals, only 17 (15,74%) were successfully “reached” for follow up interviews (see sample characteristics below in Table 4.5). The majority (94.12%, $n=16$) of the participants were males. The sample had a mean age of 29.65 years old ($SD=13.67$), and was only seen to be from the Black African (58.82%, $n=10$) and Coloured (41.18%, $n=7$) race groups.

Table 4.5 Follow-up sample characteristics (n=17)

Characteristics	Total population (n)	Percentage (%)
Gender		
Male	16	94.12
Female	1	5.88
Age categories at time of injury (mean= 33.90)		
18 - 30 years	11	64.71
31 - 45 years	3	17.62
46 - 60 years	2	11.74
61+ years	1	5.88
Race		
Black African	10	58.82
Coloured	7	41.18
White	0	0
Other	0	0
Severity		
Complete	10	58.82
Incomplete	7	41.18
Injury classification		
Paraplegic	8	47.06
Tetraplegic	9	52.94
ASIA classification		
ASIA A	10	58.82
ASIA B	1	5.88
ASIA C	2	11.77
ASIA D	4	23.53
Level of injury		
Cervical	9	52.94
Thoracic	8	47.06
Lumbar	0	0



Despite several attempts by the researcher to conduct the follow up interviews telephonically, several challenges were encountered and highlighted the difficulties often encountered with longitudinal studies of this nature in a developing country. The reasons for the “drop outs” for follow-up interviews were the phone being put down when asking to speak to the participant (1.1%, n=1), the cell phone number was no longer active (3.7%, n=4), not answering the call (9.26%, n=10), there was no contact number available for the participant from the person contacted (10.19%, n=11), incorrect telephone/cell phone numbers (12.92%, n=14), participant was reported to be unavailable (14.82%, n=16), with calls going straight to voicemail was the most prevalent (32.41%, n=35) (see in Table 4.6).

Table 4.6 Reasons for poor follow up (n=91)

Reasons for poor follow up	Male	Female	Population
	n (%)	n (%)	n (%)
Hung up the phone	1 (1.1)	-	1 (1.1)
Cell phone number no longer active	4 (3.7)	-	4 (3.7)
Not answering	8 (7.41)	2 (2.2)	10 (9.26)
No contact number available	9 (8.33)	2 (2.2)	11 (10.19)
Wrong number	11 (10.19)	3, (2.78)	14 (12.92)
Unavailable	14 (12.92)	2 (2.2)	16 (14.82)
Voicemail	31 (28.7)	4 (3.7)	35 (32.41)

Table 4.7 below highlights the follow-up variables investigated with the contacted participants. One participant started cigarette smoking during the first year following the TSCI. When compared to baseline, 5 patients continued cigarette smoking during the first year following the TSCI. The 6 participants' daily frequency of cigarette smoking, in the preceding 30 days, ranged from one per day to 20+ per day. All of the participants were male with a mean age of 32.83 years old (SD=10.3). When asked if they have consumed alcohol following their discharge from GSH ASCI unit, 2 male participants reported commencing consuming alcohol and 2 male participants continued their consuming alcohol during the first year following the TSCI. The amount of glasses consumed in the preceding 30 days ranging from two to five drink per occasion. One male participant reported consuming "too much" when he indulged in alcohol. The mean age for the 4 males was 29 years old (SD=7.62). When asked whether, if they had been diagnosed with hypertension three participants (one female and two males) reported being diagnosed with hypertension following discharge from hospital. All of these participants had not previously reported being diagnosed with hypertension. When asked if they had been put on medical management for hypertension, all three diagnosed with hypertension reported that they had been put on chronic medication.

Table 4.7 Follow-up variables assessed (n=17)

Variable	At baseline n (%)	At 1 year follow-up n (%)
Smoking		
Yes	5 (29.41)	6 (35.29)
No	12 (70.59)	11 (64.71)
Alcohol use		
Yes	2 (11.76)	4 (23.53)
No	15 (88.24)	13 (76.47)
Hypertension		
Yes	0	3 (17.65)
No	17 (100)	14 (82.35)

4.6 SUMMARY OF THE CHAPTER

The study aimed to describe the socio-demographic profile of patients admitted to the GSH ASCI unit over a one-year period following them sustaining a TSCI. It further sought to examine the causes and severity of injury sustained. The baseline risk profile for CVD was further analysed for the TSCI cohort. It was reported that 86% (n=93) of the patients admitted were males with a mean age of 33.29 years old. The main causation of TSCI in the study setting was assault (59%). Spinal injury to the cervical area (C1–8) was the most common (51%, n=55), followed closely by injuries in the thoracic area (T1-12) (40%, n=43). The mean number of days spent at GSH ASCI unit was 35 days (SD= 34.02). Several significant finds were also reported in the TSCI cohort. Of the patients questioned about CVD risk prior to the TSCI, a small percentage previously diagnosed with hypertension was observed (5.6%, n=6). More

prevalent was prior cigarette smoking (63.89%, n=69) and alcohol consumption (52.78%, n=57) in the original TSCI cohort. Follow up data one year post incident was difficult to obtain due to various factors.

Qualitative findings will be discussed in Chapter 5.



CHAPTER 5

QUALITATIVE RESULTS

5.1 INTRODUCTION TO THE CHAPTER

This chapter presents the findings of the content analysis of the semi-structured individual interviews and focus group discussions, which attempted to answer the objectives of the third phase of the study. The third phase attempted to explore the experiences of persons with a TSCI regarding their ability to be physically active once reintegrated back into the community. Specifically, the aims for the third phase were to:

- 1) Explore the experiences of individuals with TSCI regarding physical activity and how it is affected following a TSCI.
- 2) Explore the facilitators and barriers experienced by individuals with TSCI influencing their ability to be physically active after community reintegration has taken place.

This was done to establish if participants were at an increased risk of developing CVD given the decrease in physical activity levels often seen following a TSCI.

5.2 STUDY POPULATION AND SAMPLING

In order to explore the experiences of individuals with TSCI regarding physical activity and how it was affected following a TSCI, semi-structured interviews were conducted with individuals from the original TSCI cohort. The cohort therefore

consisted of individuals living with a TSCI for a minimum of one year. As stated in Chapter 3, participants were purposively selected from the original TSCI cohort and approached for participation in the semi-structured interviews. In order to explore the facilitators and barriers experienced by individuals with TSCI affecting their ability to be physically active after community reintegration has taken place, a focus group discussion was conducted. This was conducted with participants who had been living with a TSCI for more than one year and could speak of a longer-lived experience following their TSCI. While the semi-structured interviews explored CVD risk and physical activity with individuals recently reintegrated back into their communities the researcher wanted to obtain a deeper understanding of how this might change over time, hence inclusion of the focus group discussion with individuals assumed to be fully integrated in their respective communities.



The participants and results for each one of the respective objectives will be described separately below.

5.3 TO EXPLORE THE EXPERIENCES OF INDIVIDUALS WITH TSCI REGARDING PHYSICAL ACTIVITY AND HOW IT IS AFFECTED FOLLOWING A TSCI

In this section the study sample is described and the themes, which emerged from the semi-structured individual interviews, are delineated.

5.3.1 Characteristics of the study sample

The fifteen participants included in this part of the study were purposively selected from original TSCI cohort and was based on the criterion of diversity. Typically, all were telephonically approached to set up an initial meeting where the researcher explained the purpose of the study and they were given the opportunity to ask questions. Informed consent was sought at the end of the first meeting and a follow up interview was arranged at a time and place that was convenient for the participant. In an attempt to answer the first objective of Phase 3 of the study, the researcher conducted 15 individual semi-structured interviews with participants from the original TSCI cohort. The interviews were conducted with participants after a minimum of one year following their TSCI and after they were reintegrated back into their respective communities. The majority of the participants were male (86.67%, n=13), with only two (13.33%) female participants. The participants who participated in the semi-structured interviews had a mean age of 33.47 years old (SD= 11.7). Each participant was encouraged to participate in the semi-structured interviews and explore their experiences related to physical activity and how it was affected following their TSCI. The demographic information of the participants is summarised in Table 5.1.

Table 5.1 Characteristics of individual interview participants (n=15)

ID	Age	Gender	Level of Injury	Employment Status
1	37	Male	Paraplegic	Unemployed
2	35	Male	Paraplegic	Unemployed
3	20	Male	Paraplegic	Unemployed
4	21	Female	Paraplegic	Unemployed
5	32	Male	Paraplegic	Unemployed
6	22	Male	Tetraplegic	Employed
7	42	Male	Paraplegic	Unemployed
8	23	Male	Paraplegic	Unemployed
9	62	Female	Paraplegic	Unemployed
10	47	Male	Paraplegic	Unemployed
11	32	Male	Paraplegic	Unemployed
12	39	Male	Tetraplegic	Employed
13	40	Male	Tetraplegic	Employed
14	21	Male	Paraplegic	Unemployed
15	29	Male	Paraplegic	Unemployed



5.3.2 Emerging themes from individual semi-structured interviews

Thematic analysis of the semi-structured individual interviews identified three (3) major themes and seven (7) sub-themes from participants who sustained a TSCI and were integrated back into their respective communities. The themes and sub-themes identified fall under both domains of the ICF classification specifically the:

- 1) Functioning and disability; and
- 2) Contextual factors.

Impairments as described within the ICF framework are problems in body function and structure causing a significant deviation or loss. Body function examines physiological functions of body systems whereas body structures look at anatomical parts of the body such as organs, limbs and their components. The ICF conceptualises environmental factors in the five domains namely: (1) natural environment and human-made changes to environment, (2) products and technology, (3) support and relationships, (4) attitudes and (5) services, systems and policies (WHO, 2001). Individuals with a TSCI expressed their experiences as it related to them attempting to attain optimal health after they were reintegrated back into their respective communities (as see in Table 5.3).



Table 5.2 Outlines the themes and sub-themes that emerged during analysis of semi-structured interviews

THEMES	SUB-THEMES
BODY FUNCTION	<ul style="list-style-type: none"> • Pain • Weakness • Mental health • Activities of daily living
CVD RISK	<ul style="list-style-type: none"> • Knowledge and awareness of CVD risk
NATURAL ENVIRONMENT	<ul style="list-style-type: none"> • Home environment • Leisure and recreational activities

Verbatim quotes were used to further exemplify the above-mentioned themes illustrated.

Theme One: Body function

The researcher explored the specifics around how participants' body functions were affected after sustaining TSCI and impacting their ability to be physically active. Participants reported a range of health problems experienced at home following their discharge from rehabilitation. These are discussed below under the relevant sub-theme.

Sub-theme 1: Pain

Pain often impedes function whether in the abled bodied population or the disabled population. It often affects every aspect of a person's life and cause conflict between what their minds wants to achieve and what their body allows them to do (Skjutar & Müllersdorf, 2010). As individuals came to terms with their altered functional abilities, after being reintegrated back into their community, they experienced several body function challenges. Pain was identified as a considerable challenge faced by many of the participants after their TSCI, affecting their ability to be physically active as they fear more injury, as an example, demonstrated in the comments below.

“So ok when the pains comes it’s like affecting my whole spine making me, I can’t move, it’s like my legs is heavy. It’s like my left arm is heavy. It doesn’t come a lot so when it comes, it comes heavy I need to rest a while.” (Participant 12, male, 39 years)

“If I get back pain because you know I’m in a wheelchair. If I get back pain and getting to the vehicle and out it’s working on my back and I don’t like it. I don’t like it because of the operation man. I am so scared that I will get hurt.” (Participant 4, female, 21 years)

“You know the accident really affected.... my neck... No, the pain like you know, the neck... I can turn freely to the right but to the left I need to turn my body.” (Participant 13, male, 40 years)

Subtheme 2: Weakness

Further implications were seen with regards to body function following their TSCI. Participants identified weakness and limb contractures as a considerable challenge after their TSCI affecting their ability to be physically active. This is a common occurrence following a SCI as normal motor and sensory functioning below the level of the spinal cord damage are affected impacting individuals' ability to use the affected limbs meaningfully.

"I'm walking but not like before cause the strength isn't always there." (Participant 12, male, 29 years)

"You know mos, we get contractures... If you not active your arms and legs they like contract into a position. You unable to put on your clothes. You unable to eat or do anything now cause you not active and you not using your arms. Your legs. After a while you not really able to do anything to make your arms and legs straight and sit up straight." (Participant 10, male, 47 years)

"Like I must rest a lot before I can do stuff and challenging that you can't do what I want to do." (Participant 11, male, 39 years)

As participants emerged from hospital following their TSCI and reintegrated back into their respective communities, they faced the challenge of an altered body function within their specific home and community context. A large portion of the individuals interviewed highlighted that their ability to be physically active and engage in their environments were often impeded by body function citing pain, weak or stiffness as common causes.

Subtheme 3: Mental health

Altered body image and function experienced by individuals following a TSCI often results in negative mental health as they come to terms with their new reality. This is often accentuated once they are discharged from hospital and reintegrated back into their respective communities where they experience a reduction in their previous functional capabilities. Many of the participants highlighted that mental status was a key component affecting their willingness to be physically active. Negative emotions experienced by participants are illustrated in the comments below.

“A lot of issues, a lot of issues.... I started giving up on life. Everything got worse. Life got miserable. It just got horrible.... until one day when I woke up and thinking that things is so bad that I might as well die.... The depression would have killed me. The weight and all of that kind of stuff would have killed me.” (Participant 10, male, 47 years)

“Um, I, I don't feel okay about it because with this wheelchair I can't go anywhere because I need someone to push me wherever I go.” (Participant 3, male, 20 years)

“Sometimes I feel like I am a burden to other people and stuff like that, especially when, (getting emotional and her voice is breaking) especially when the whole family go out and stuff like that. Then, there is always something popping and there's something going wrong and stuff like that.” (Participant 4, female, 21)

The negative emotions experienced by participants often were as a result of the drastic changes in their functional abilities after being returning home from hospital and their altered ability to be physically active whenever they wanted to be. Some participants cited things like “I feel like I am a burden” and “The depression would have killed me” highlighting the extremes of their negative emotions. However, despite many negative emotions, several participants commented on the benefits of

having a positive attitude and how the positive shift in their mental health had assisted in their overall ability to be physically active.

“Just having a positive and clear mind and just telling yourself ja and even the hospital and the surgeon helped and now you out it’s all up to you to work and exercise yourself and to work your muscles back to normal.” (Participant 14, male, 21)

“I’m getting more and more positive... More people talking to me like inspiring me and like giving me ways to cope or things I think I could achieve its like so ja it’s all because, I just think lucky man. All you guys give me, showing me the way and help me and guiding me along the way.” (Participant 10, male, 47 years)

One participant reflected deeply about her experience and the positive changes she made after being reintegrated back into her community.

“I have changed. I’ve grown up and a lot of things have happened. While I was still in hospital, my brother also got stabbed and he didn’t survive (verge of tears). I’m getting a little emotional now. But ja man it’s why I don’t want to put myself into things that’s not going to work out man (trembling voice).” (Participant 4, female, 21 years)

While participants came to terms with the effects of their TSCI, after returning home, their mental health was a major influencing factor affecting their overall desire to engage in any type of physical activity. The shift from negative attitudes initially after coming home to that of a more positive outlook over time was a key facilitator highlighted by some of the participants.

Subtheme 4: Activities of daily living

It is assumed that if participants cannot function optimally within their everyday life, it will have an impact on their ability to be physically active. From the interviews it became clear that individuals struggled with some of their activities of daily living and therefore their ability to function optimally within their context as illustrated below:

“Just the mere fact you can’t actually just come back and do everything that you were able to do before the injury.... so just that is a little bit of a negative because now you can’t do anything that you used to.” (Participant 14, male, 21)

When asked what function specifically was affected following their TSCI and after returning home, two participants reported:

“... obviously not picking up heavy objects is something I don’t do but I can pick up things if I chose too but I don’t choose to cause the strain, cause the strain on my back.” (Participant 8, male, 23 years)

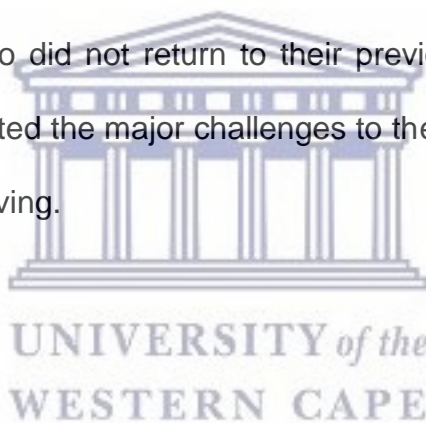
“I’m walking but not like before cause the strength isn’t always there.... I feel the numbness in my legs or in my hips or in my spine or in my back it feels like my back is heavy.” (Participant 15, male, 29 years)

In contrast with the participants who shared experiences in relation to decreased function, some participants shared their full return to their normal state as illustrated below.

“Running and walking, swimming and driving and doing anything.” (Participant 7, male, 42 years)

“Yes, yes I’m back to normal. I can walk again. I was thinking I’m not going to walk in the mall.... but now I feel good.... Yes, I do the washing I do the windows, the floors I do everything.” (Participant 9, female, 62 years)

There were contrasting perspectives put forward by the participants interviewed. Some highlighted considerable challenges with their activities of daily living. One of the participants stated that after her TSCI, it negatively affected her ability to be physically active, citing that “you can’t actually just come back and do everything that you were able to do before the injury”. Several other participants highlighted their speedy recovery following their TSCI and were back to previous physical activity levels. The participants who did not return to their previous physical activity levels were the ones who highlighted the major challenges to their abilities to carry out their previous activities of daily living.



Theme Two: CVD risk

Given the study hypothesis that individuals with TSCI were at a greater risk for developing CVD due to their subsequent sedentary lifestyle the researcher wanted to explore the knowledge and awareness participants had with regards to CVD risks in addition to guidance or advice given by health care professionals in this regard.

Sub-theme 1: Knowledge and awareness of CVD risk

When asked whether participants had been diagnosed with CVD after their TSCI the

majority of the participants indicated that they had not been diagnosed with CVD as illustrated in the comments below.

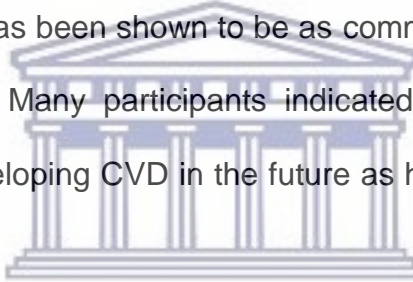
“nothing.” (Participant 6, male, 42 years)

“No, nothing.” (Participant 8, male, 23 years)

Only one male participant from the cohort reported having been diagnosed with a chronic disease since being discharged from hospital.

“I got high blood pressure.” (Participant 13, male, 40 years)

The development of CVD has been shown to be as common in the SCI population as in the general population. Many participants indicated that they were concerned about the possibility of developing CVD in the future as highlighted by the comments below.



“I’m more at risk of getting all of these diseases and all these stuff because I’m fat and because I’m not so active like other able body peoples. for me to be extra cautious of how I live and it’s up to myself.” (Participant 10, male, 47 years)

“Probably if I don’t keep fit and exercise enough it will be my own fault. Mmmm but ja can be that my back would start giving problems. If I do keep fit and strengthen my back now that wouldn’t be a problem in the future, now so that is all in my hand basically.” (Participant 8, male, 23 years)

Sub-theme 2: Advice from health professionals regarding CVD

Knowledge about CVD is crucial in curtailing the onset of CVD within any population, but specifically in the SCI population. Individuals, however, need to be advised

accordingly, if their knowledge is to be improved. Conflicting views regarding this was seen from the interviews. When probed as to whether they had received any prior information about CVD from healthcare professional while in hospital, the majority of participants reported receiving little to no information while in hospital, as illustrated in the comments below.

"No advise. Nothing." (Participant 13, male, 40 years)

"No." (Participant 15, male, 29 years)

"... lack of information." (Participant 10, male, 47 years)

In contrast to the above, one participant reported being told regularly about CVD from healthcare professionals while in hospital.

"I know they spoke about all of this stuff (CVD). They sounded like a broken record thing. Every time is like when they look at me it's they had to tell me about this kind of stuff. They actually spoke to my caregiver to watch me a lot about what I'm eating. I was like gaining a lot of weight and stuff." (Participant 10, male, 47 years)

When asked whether they felt there was a need to receive more information about CVD from a healthcare professional, several participants reported that they thought it would be necessary as indicated in the comments below.

"I think maybe there could be someone that could explain to me." (Participant 15, male, 29 years)

"Yes, I think so ja." (Participant 12, male, 29 years)

"Yes, if they can tell me more about it." (Participant 9, female, 62 years)

“Yes. Possibly yes because ja I would like that.” (Participant 8, male, 23 years)

When asked why they thought the information related to CVD would be important for them following their TSCI one of the participants reported that they thought it would be necessary to avoid it in the future.

“I think it is yes, it is... So I can try and avoid them so... I might think that I’m safe and then all of a sudden, I might get them who knows.” (Participant 15, male, 29 years)

Participants were seen to be concerned with the development of CVD in the future. Although conflicting views with regards to information received from healthcare professionals were observed, the need for targeted CVD risk education in this population is highlighted. Many of the participants highlighted that they were interested to know more about CVD and the researcher is of the opinion that this information is best suited to be delivered while in hospital, where individuals might be the most receptive to health advice and preventive measures can be advised prior to them being reintegrated back into their respective communities.

Theme Three: Natural environment

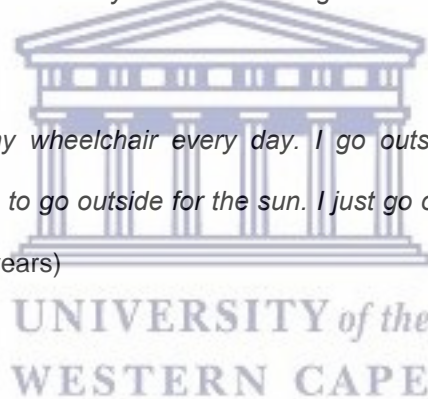
After being reintegrated back into their respective homes and communities, participants faced numerous barriers that impacted their ability to function and feel part of their social circles. This varied from challenges at home to participation in recreational activities as illustrated in the sub-themes below.

Sub-theme 1: Home environment

Individuals who sustain a TSCI are often faced with a myriad of challenges after returning to their home environments. This is often as a result of altered functional abilities experienced, with many of them now being in a wheelchair unable to negotiate their home environment in the same way as before. Many of the participants interviewed commented that following their TSCI and subsequent reintegration back home, the adjustment to their home environment was fraught with considerable challenges that lead to participants having to lead a sedentary lifestyle as illustrated below:

“Um... I’m just watching TV all day there. Is nothing else I am doing.” (Participant 3, male, 20 years)

“I’m sitting around in my wheelchair every day. I go outside here by my home but only sometimes. I just like to go outside for the sun. I just go out to see the sun for my health.”
(Participant 5, male, 32 years)



The sedentary lifestyle experienced by many of the participants after the TSCI was a noteworthy variable, as this was part of the hypothesis of the researcher. There were no facilitators highlighted by any of the participants interviewed. Limited activities at home seemed to be a major frustration for many of the participants. Overall, participants had considerable challenges to being physically active within their home context after their TSCI and this affected their ability to engage in any meaningful activity within their home.

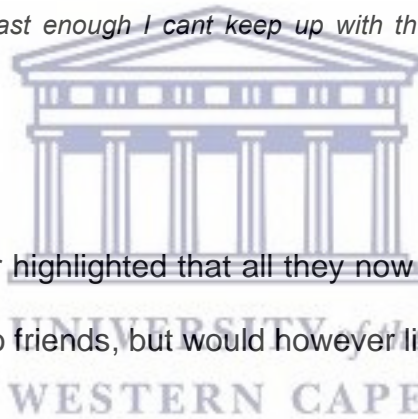
Sub-theme 2: Leisure and recreational activities

Participating in previous hobbies or recreational activities following a TSCI is often fraught with challenges as a result of changes to individuals' functional capabilities. When participants were asked whether they engaged in any recreational activities that required them to be physically active, many of the responses by participants highlighted that they had stopped since their TSCI as see in the comments below.

"Sometime I used to like to play soccer but now I cannot." (Participant 1, male, 37 years)

"I gave up playing soccer and all of that" (Participant 14, male, 21)

"Yes I do I like to play soccer not professionally but as like a serious hobbies but I'm not allowed to like I'm not fast enough I cant keep up with the pace." (Participant 2, male, 35 years)



One participant in particular highlighted that all they now engage in more sedentary activities such as chatting to friends, but would however like to do more.

"No, I am just sitting here chatting that's all we do. Well as long as they [friends] are here with me I am happy, 'cause we are just sitting and chatting here... I would like to go outside if I can push myself and if my chair can go there outside I would go out." (Participant 3, male, 20 years)

One of the participants reported dj-ing (playing music at social events) as a hobby but subsequent to his TSCI, stopped because he was physically not able to do it anymore due to changes to his functional abilities as seen in his comments below.

"... it [dj-ing] requires a lot of physical work as well. With the set up and the break up and the whole getting from and the whole set up of events it's a lot of work so that side of it I can't. I

absolutely cut it out 'cause I am not able to carry things anymore." (Participant 2, male, 35 years)

In contrast with the participants who shared experiences in relation to decreased engagement in recreational activities, some participants highlighted that they were engaging in some sort of recreational physical activity as seen in the comments below.

"Yes, I go to the gym. I do exercise." (Participant 9, female, 62 years)

"Right beside the program that I'm part at Newlands that I'm part of. I get three sessions per week. Three days I go there where I do intensive exercise ja. I do my intensive exercise with all the other guys in the program." (Participant 10, male, 47 years)

Some participants engaged in exercise but were still fearful of doing more damage to their body following their TSCI as seen in the comments below.

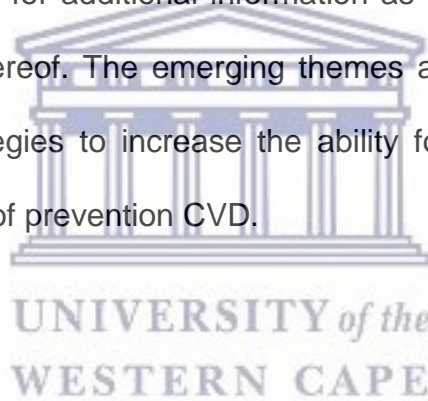
"No, I do my own self.... nobody can tell me I must do exercise but I'm very careful about my neck and stuff like that." (Participant 9, female, 62 years)

"Ja you know like my neck like ja and trying to exercise... the metal they put in the neck I don't know maybe if they remove the metal or the metal will stay there forever." (Participant 13, male, 40 years)

The ability to engage in recreational activities was negatively affected by many of the participants interviewed. This resulted in an overall decrease in their physical activity levels within their broader community context. A few participants, however, were

engaging in some physical activities, but this was a small portion of the cohort interviewed.

In summation the semi-structured interviews yielded a wealth of information from participants as they attempted to engage in some sort of physical activity within their homes and broader community following their TSCI. What was apparent was that the participants faced considerable internal and external challenges, which negatively affected their ability to engage in physical activity as they attempted to optimise their health status. While HPT was only seen in one of the participants, CVD education was still flagged as a point for additional information as individuals sought to curtail the future development thereof. The emerging themes and sub-themes highlighted the need to develop strategies to increase the ability for individuals to engage in physical activity as means of prevention CVD.



5.4 TO EXPLORE THE FACILITATORS AND BARRIERS EXPERIENCED BY INDIVIDUALS WITH TSCI INFLUENCING THEIR ABILITY TO BE PHYSICALLY ACTIVE AFTER COMMUNITY REINTEGRATION HAS TAKEN PLACE.

In this section the study sample is described and the themes, which emerged from the focus group discussion, are delineated.

5.4.1 Characteristics of the study sample

Convenient and purposive sampling of additional participants was done for inclusion in the focus group discussion. Participants were invited to a meeting arranged by a

not-for-profit organisation where the researcher explained the purpose of the study and they were given the opportunity to ask questions. Informed consent was sought at the end of the first meeting and a follow focus group discussion was arranged at a time and place that was convenient for all the participants. The focus group discussion consisted of nine male participants who had been discharged from hospital, had been living with a TSCI for longer than a one and half years and who consented to participate in the focus group discussion. The focus group discussion cohort had a mean age of 45.11 years (SD = 10.38). The focus group discussion took place in a relaxed and convenient setting for the participants; a community hall was used for this purpose. Each participant was encouraged to participate in the discussions and explore the facilitators and barriers experienced by individuals with TSCI influencing their ability to be physical activity after community reintegration has taken place. The demographic information such as age, gender, and level of injury and employment status of the participants are summarised in Table 5.3.

Table 5.3 Characteristics of FGD participants (n=9)

ID	Age	Gender	Level on injury	Employment status
CM	54	Male	Paraplegic	Unemployed
RE	56	Male	Paraplegic	Unemployed
RB	43	Male	Tetraplegic	Employed
TC	42	Male	Paraplegic	Unemployed
AG	42	Male	Paraplegic	Unemployed
AS	54	Male	Paraplegic	Unemployed
SR	23	Male	Tetraplegic	Unemployed
MC	52	Male	Paraplegic	Unemployed
MA	40	Male	Paraplegic	Unemplpued

5.4.2 Emerging themes from focus group discussion

Thematic analysis of the focus group discussion identified three (3) major themes and seven (7) sub-themes from participants who sustained a TSCI. The ICF was again used as the over arching framework to report on the themes and subthemes that emerged from the focus group discussion with participants, living with a TSCI for a longer period than the participants from the individual interviews. The themes and sub-themes identified in focus group discussion are presented in Table 5.4.

Table 5.4 Outlines the themes and sub-themes that emerged during analysis of focus group discussion

THEMES	SUB-THEMES
ENVIRONMENTAL FACTORS	<ul style="list-style-type: none">• Home environment• External environment• Natural environment• Leisure and recreational activities
TRANSPORTATION	<ul style="list-style-type: none">• Public transportation• Private transportation
SERVICES, SYSTEMS AND POLICIES	<ul style="list-style-type: none">• Government

Theme One: Environment Factors

According to Kostanjsek (2011), environmental factors, one of the domains of the ICF, have an impact on all components of functioning and disability and are organised in sequence from the individual's most immediate environment to the

general environment. Individuals who sustain a TSCI are expected to engage in their home environments and the broader context within their respective communities and pick up their roles from before the injury. Several of the facilitators and barriers experienced by the participants of the focus group discussion are highlighted in the sub-themes below.

Sub-theme 1: External environment

Some participants, when engaging in physical activity, encountered several barriers namely stairs, poor access for disabled persons, and terrain issues. These barriers impeded their ability to be physically active and can be seen in the excerpts below.

"The turnstiles... it's always a problem for me. Irrespective of whether you go with the crutches or the wheelchair, because if you're in the thing (turnstile) and the thing turns, you have to move at the same speed... if I walk through, maybe my crutches, or maybe the thing is too fast for me, and so one can get trapped in that thing. " (TC, male, 42 years)

"And after my injury, I cannot do certain things because of accessibility ... yes, if I might take my wheelchair ... how should I say ... wheelchair racing then I think first of all, I must first look at which route is available to me, I can not just drive on any road, because all the roads are not made for wheelchairs." (TC, Male, 42 years)

This was contradictory to the comments of another participant who reported access at a mall, and other places, as a facilitator to his physical activity, as seen in the comment below.

"... at the Promenade Mall... there are convenient ramps to use. And the place where our sports centres are is convenient. Where we have to come in. And at the pool tables, where we have to shoot is a little convenient." (MC, male, 52 years)

One participant reported noteworthy insights received from a family member as it pertained to access for the disabled population as demonstrated in the comment below.

“What I actually think, sometimes it’s not... like my brother Anthony says... sometimes it’s not, how can I say, it’s not the barriers actually that disabled people, it’s the environment, because the environment is not wheelchair accessible and that becomes a barrier for yourself, because that disables you.” (CM, male, 54 years)

Despite attempts to engage in physical activities within their respective communities, stairs were identified to be a major barrier because people were often required to assistant participants, but this resulted in several psychological implications as illustrated in the comment below.

“One of my baddest experiences that I had with staircases is when I went to... I actually facilitated a lecture at UCT and I had 4 guys actually carry me down. You know what the staircases look like, it’s about 30 steps and that was a very scary experience for me... Staircases are a big problem because you actually are trusting other people with your safety.”
(SR, male, 23 years)

“On the stairs, you need to be helped by a walking person, and that is something that is uncomfortable for me.” (MC, male, 52 years)

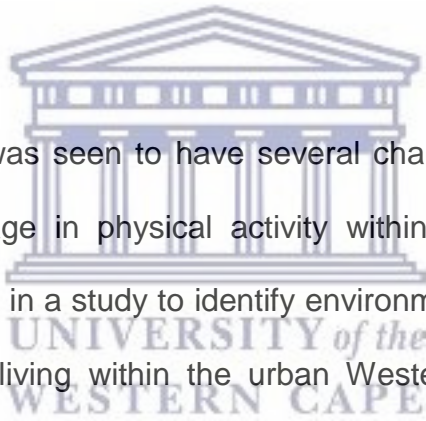
One of the participants highlighted how a facilitator could act as a barrier too, and how one can easily use the environment at work to be physically active.

“... a very long passage... it’s actually of the hospital where I work and I see that as a facilitator. It’s very quiet there; I work long hours, so I have the opportunity to push myself in my wheelchair up and down there. However, it’s also a barrier sometimes, because it’s not

always available. Sometimes there are patients there or management feel that it is not safe for me to do so, they prevent me to do that.” (SR, male, 23 years)

Individuals with TSCI often have to access community health centres (CHC) for ongoing rehabilitation or medication. This is crucial in their management of medical conditions such as CVD. One participant identified barriers to accessing their local CHC as illustrated in the below comment.

“As you can see there’s a ramp – the ramp is not properly built and sometimes you struggle to get in there... but the other thing is, to get to the facility is a bit of a problem because I also stay about a kilometer or 2 away from the facility.” (CM, male, 54 years)



The outdoor environment was seen to have several challenges for individuals with TSCI when trying to engage in physical activity within their broader community context. Maart et al., (2007) in a study to identify environmental barriers experienced by persons with disability living within the urban Western Cape region of South Africa, reported that 50% of the participants highlighted barriers when access public buildings. This resulted in a negative impact on mobility. This is of concern, as this study was conducted seven years after the publication of the INDS of South Africa (1997), which recommends (recommendation 5d) that the National Building Regulations be amended to allow barrier-free access and proposes measures to ensure implementation of these regulations (Maart et al., 2007). More than twenty years down the line, this still seems to be a challenge faced by this disabled population.

Sub-theme 2: Natural environment

The natural environment also posed several challenges when participants wanted to engage in physical activities within their communities. The wind was highlighted to be a formidable challenge as illustrated in the comments below.

"If the wind is blowing down, like today the wind is blowing 50, it's very heavy to travel with a wheelchair to the facility." (CM, male, 54 years)

"I come through myself, I pushed a lot of heavy this afternoon, this morning against the wind. I mean, the wind hit me so, but I've come to here, but if I drive again, I'm going to ride along with the wind. " (AG, male, 42 years)

Furthermore, the weather was also seen to be a consideration when participants want to engage in physical activities.

"If I use the wheelchair, then I have to check the weather. Now, sometimes it's impossible for people who are disabled, but many times we have to study the weather because are we going with the wind all the things we look at. Because sometimes we have to look right, okay, the wind blows like that, right now we are going have a nice drive. Then we have to think about the return and the short paths we can now take, will the wind be back and so on. And sometimes, the wind is so strong, that we cannot get through to it because why, the wind blows dangerously, or sometimes it rains, the rain also keeps us down, and so on. And it's not every day that we have taxi fare." (TC, male, 42 years)

The barriers faced by participants of the focus group discussion, in their natural environment, far outweighed the facilitators, ultimately negatively affecting their ability to be physical active and engage meaningfully in their respective communities. This

places them at risk for developing CVD due to decreased ability to engage in meaningful physical activity.

Sub-theme 3: Leisure and recreational activities

Many of the participants who participated in the focus group discussion expressed an awareness of the importance of physical activity for their overall health. This was evident in their physical activity level prior to their TSCI, with the majority of the participants being engaged in some sort of physical activity as see in the comments below.

“I was always aware of the benefits of being physically active, and also because being active leads to being fit. Also if you are fit there is health benefits. You don’t get ill easier. It’s more difficult for you to catch a cold when you’re fit, than when you’re not fit. I knew the benefits by being active. I used to play soccer when it’s winter, soccer season, and when it’s not soccer season, I used to play volley ball.” (RB, Male, 43 years)

“Yes, I was very active in my sports... I played cricket. I played soccer. I played netball. I played rugby.” (AG, Male, 42 years)

“Before I had my, I was very active with sports. I did things like running. I did soccer. I was very active with sports.” (TC, Male, 42 years)

The researcher wanted to explore whether participants were aware of the health benefits of being physically active once reintegrated back into their communities. The majority of the participants in the focus group discussion were acutely aware of the benefits of engaging in physical activity post TSCI. Many of who highlighted a desire to engage in physical activity as illustrated in the comments below.

“So I know the benefits and then the gap in my life was when the accident happened, and the rehab. In those few months, I saw what can happen if you’re not physically fit. And then also, with the limited function I have left, I saw that I need to strengthen myself and use the muscles I can still use. So that is why, being physically fit and being able to participate in a training programme or any activity, it is actually vitally important for me now. Much more now that I am physically disabled, than when I was an able-bodied person.” (RB, Male, 43 years)

“I think it is very important (being physically active) because for me, I’m discovering very stiffness in my body” (SR, Male, 23 years)

“All disabled people, I recommend that they should not be so still. They must keep themselves active, in their disability. To stay healthy.” (AS, Male, 54 years)

“nothing is impossible when you’re in a wheelchair. So you can still do the things that you want to do.” (AG, Male, 42 years)

After their TSCI, and after being integrated back into the community some participants attempted to remain physically active by participating in numerous sporting activities as highlighted in the comments below.

“My main sport that I actually play is wheelchair basketball... I do my wheelchair basketball outside.” (AG, Male, 42 years)

“So currently I’m involved with wheelchair rugby, and I joined the gym on a regular basis.” (RE, Male, 56 years)

“I actually relied on some of my colleagues to take me to wheelchair rugby” (MA, Male, 40 years)

The researcher was interested in understanding whether participants encountered any barriers with regards to being physically active within their communities. Despite

being aware of the importance of physical activity, many participants encountered obstacles attempting to engage in numerous physical activities as seen in the excerpts below.

“And with my dancing, actually, I don’t do dancing anymore because of transport problems and there’s a little more problems... wheelchair rugby, I actually relied on some of my colleagues to take me to wheelchair rugby... And that’s in Stellenbosch... so if my driver is not there, so then I actually sit at home. So there’s no sports for me after that.” (MA, Male 40 years)

“I have the wheels that I can put on to go play rugby, but I cannot go and get it myself. So that is a barrier for me, assistance when you want to exercise, or participate in a training programme.” (RB, Male, 43 years)

“... the gym that I have, and at the time there, there’s a bag placed on top of it, my spare wheelchair is standing next to it with the wheels there. It’s not being used for the purpose it has been donated to me. It was donated to me because I was active and I can’t use it. But at that point, my family decided that’s a good place to put my stuff and store it, because I’m not able to use it independently. So when I want to use it, I must first make arrangements, ask them to assist and so. That concludes all the pictures that I took of the barriers in my life for participating in the exercise programme.” (RE, male, 56 years)

One participant highlighted challenges with access to a space for recreational activities and the unwillingness of the owner of the facility to make changes to accommodate people in wheelchairs, as seen in the comment below.

“... a fitness centre or so, but it’s an area that can be used. I have approached a person there on 2 occasions for us to have a meeting... because that is big enough where we can have a game of darts or dominoes, but we cannot get into it. It’s available free of charge, but we

cannot get into it. The access is an issue. And the owner of it also is not interested in making a ramp there or allowing us to get someone to make a ramp there.” (RE, male, 56 years)

Another participant reported being fearful of getting injured on the basketball court negatively affecting his ability to engage in a physical activity within his community as illustrated in the comment below.

“... the basketball court is a tar court, it’s... and sometimes it’s very dangerous to play basketball on a tar court. As you know, basketball is a contact sport. It’s a very fast sport to play with wheelchairs. Sometimes the wheelchairs bump into one another, and you fall and... you fall on the tar and you injure yourself.” (CM, male, 54 years)

Some participants cited health issues as a factor affecting their ability to be physical active and engage in recreational activities as see in the comments below.

“I’m discovering very stiffness in my body and I can see that by not exercising, I think I’ve competed in something and they asked do you exercise and I felt very guilty and I’m very stiff because sometimes you have to go to bed, and some place, wrong place, you get a spasm in the wrong places. So some people don’t know how to... like in... how to help you, because you can fall out of your wheelchair, just by a spasm by not being active.” (SR, Male, 23 years)

“And it’s not always what we ... what can I say is healthy, pushing ourselves to the clubhouse to practice or not. And you should always seek someone to help you too, occasionally.” (AS, male, 54 years)

In summary, with community access being a critical component to reintegration, all the participants in the focus group discussions had concerns around how this was supposed to be realised by them following their TSCI, and subsequent lived

experience. Despite their awareness of the benefits of being physically active, many of the participants encounter barriers to achieving this outcome. Many of the participants cited accessibility issues, some of which could be addressed by local stakeholders while other participants highlighted concerns around the weather, which was not necessarily something they could control. What was apparent was that there were considerable environmental barriers faced by participants when wanting to engage in physical activities and few facilitators.

Theme Two: Transportation

Transportation is an important resource for the general population, but even more so for the disabled population, as it connects people to the broader society and allows them to engage in numerous activities one which is recreation activities outside of their home. Lin, Hwang, Yu and Chen (2009) investigated subjects with SCI and reported that transportation was one of the most important barriers with regard to returning to productive activity; and of interest in the current study, physical activity. With this background, and the fact that all the participants highlighted major concerns around transportation, the researcher sought to understand how transportation affected their ability to engage in various physical activities outside of their home. Accessibility and feasibility were cited as major barriers to their ability to participate meaningful within their community and further limited their ability to be physically active. This emerged as one of the major barriers experienced by the focus group cohort, as transportation was the medium used to get to various recreational activity venues and facilities.

Sub-theme 1: Public transportation

All the participants highlighted major concerns around transportation accessibility and feasibility. This would often result in participants opting to rather stay at home and not engage in physical activity whether it is through formal or informal mechanisms. Participants highlighted transportation as a major barrier for them as disabled persons and is illustrated in the comments below.

“Transportation is a very big challenge for us.” (TC, male, 42 years)

“Transportation is the biggest barrier we face as disabled people.” (CM, male, 54 years)

With transport being highlighted as a major barrier to community integration as seen in the comments above, it was hypothesised that less physical activity would result from the decreased engagement in broader community context. Reasons as to why transport was seen to be such a major barrier for participants were explored. Accessibility when trying to engage with various transportation services was identified as a main reason as illustrated by the comments below.

“So there is no accessibility for people who are disabled like at the train and at the station. The toilets. There is also not always accessibility for people at the toilet. What stops me? Like, for example, the stairs, the ramps, that stops for me to come out” (AJ, male, 42 years)

“I took the liberty of going to the bus stop, and check if there was a ramp close to the bus stop, which there was none.” (RE, male, 56 years)

“Now the transport from there is also sometimes a problem, for you in a wheelchair because the taxis are not accessible for wheelchairs” (MC, male, 52 years)

“The transportation is not accessible to you, which really frustrates some of the disabled people, and I can understand that some of us get cross, some of us get frustrated, and we

pick fights with the taxi rank, we pick fights with Golden Arrow, we pick fights with the transportation company, because they don't cater for disabled people. The City bring a project, My Citi, they made us promise, when My Citi come out, it will be wheelchair accessible, it will be wheelchair friendly, disabled people will be able to drive in the bus.” (CM, male, 54 years)

Contradictory to the access issues highlighted by the participants above, one participant commented positively about the taxi rank in his local community and reported it as a facilitator to his community engagement and physical activity level.

“The taxi rank is wheelchair accessible, here... it's very wheelchair friendly, there's a lot of ramps.” (CM, male, 54 years)

When making use of public transport in South Africa, commuters often use minibus taxis to access their respective communities and be physically active. This is especially the case in the communities represented by many of participants from the focus group discussion. Some of the participants reported that when making use of public transportation, specifically minibus taxis, wheelchair access was an issue along with the added cost of having a wheelchair take up space in the minibus taxi.

“The taxi itself is not actually wheelchair friendly... If I were to get into the taxi then I need to get somebody to lift me out of my wheelchair and put me into the taxi. And most of the times, the taxi drivers, they don't pick up people with wheelchairs because if they pick up people with wheelchairs then the wheelchair took away a place, unless you are willing to pay for the seat.” (CM, male, 54 years)

Similarly, participants reported additional barriers to making use of transport services, whether public or private transport services, related to its perceived high cost as illustrated in the below comment.

“The travelling fare is R13 to Cape Town. I need to pay R13 for my wheelchair as well, which costs me R26. Now, that is a barrier for me... that is a handicap for me because that actually disables me to go to town like other people. And the taxi is still the cheapest because if I ask someone with the car, he will ask me R100 to go to town, because the petrol is very expensive.” (CM, male, 54 years)

“... it's not every day that we have taxi fare.” (TC, male, 42 years)

Sub-theme 2: Private transportation

According to a study conducted by Carpenter, Forwell, Jongbloed, and Backman (2007), amongst persons living with SCI, satisfaction with their main form of transport was clearly enhanced by owning a vehicle. One participant was fortunate to have their own transportation and identified this as a facilitator to community access and overall physical activity levels within his community.

“Yes, fortunately for me. The reason I can say I'm functional with transport, I work and I can afford to have my own vehicle.... But I find that having my own vehicle and being able to afford it at the time is actually making it easier for me to get to a training center or to wherever activity is taking place.” (RE, male, 56 years)

Cost was also seen as a challenge by the participant who had their own private transportation as illustrated by the comment below.

“However, there are also added factors that hampers it, like the ever-increasing price of fuel.”

(RE, male, 54 years)

The ability to be mobile within communities is a key component to individuals with TSCIs' being able to engage in physical activity. This was seen to take place through the use of public and private transportation by the participants in the focus group discussion. What was evident in the comments from participants was that they felt disconnected from their respective communities due mainly to transportation issues. While participants reported mixed feelings around the facilitators and barriers experienced by them as it pertained to transportation, participants were clear on the importance of this element in being able to engage in physically activities outside of their home.



Theme Three: Services, Systems and Policies

Individuals living with a TSCI for a longer period of time than the original TSCI cohort of this study reported more on the role of government and its responsibility to facilitate the disabled community's access to transportation and buildings, thereby allowing them to improve their community reintegration and physical activity levels.

Sub-theme 1: Government

While participants acknowledged that the local government had made attempts to accommodate the disabled population from an environmental, transportation and accessibility perspective, they highlighted many shortcomings and oversights that

impeded their ability to be physically active. This is evident in some of their excerpts below.

“They built it, they built the facility, with the good intentions to build it for disabled people but because of the... how can I say... of not confronting us, of not consulting with disabled people, they always do the wrong thing.” (CM, male, 54 years)

“That is my problem. I would like the government to look at an integrated transport system that works within the township” (CM, male 54 years)

Participants alluded to a proactive approach in keeping government accountable to the disabled population as seen in the comments below.

“That’s why I say, we have to take responsibility to keep government on its toes to make sure they implement the legislation that is there” (CM, male, 54 years)

“If the government comes up with projects to help disabled people, man, I would just like them to take people who are disabled and ask them how things should be done or what are the obstacles because I can see they try but they do not use disabled people to give their input. Therefore there are many flops, the things are done, but it is not done right.” (TC, male, 42 years)

While trying to participate in activities within their respective communities, some participants highlighted concerns around safety within their communities. This may lead them to rather choosing to stay indoors and not engage in physical activities citing fears around being robbed/accosted as seen in the comments below.

“You see, everything you must be worried about, are you going to get robbed?” (SR, male, 23 years)

“I was accosted on 2 occasions by someone that was very interested in my cell phone. Luckily for me, I did not have it with me.” (RE, male, 56 years)

The “government” was seen to be doing something, but many participants felt that they were not consulted properly to make sure that the actions taken to assist the disabled population was actually going to be beneficial. Safety within communities was also highlighted as a major barrier when considering engaging in community activities. These challenges all negatively impacted on participants’ ability to be physically active within their respective communities.

The facilitators and barriers noted from the focus group discussion paints a bleak picture that overall barriers to engaging in physical activity far outweighed the facilitators. This negatively impacted participants’ ability to be physically active thereby increasing their risk to developing CVD in the foreseeable future.



5.5 SUMMARY OF THE CHAPTER

The study aimed to explore experiences of persons with a TSCI regarding their ability to be physically active once reintegrated back into their respective communities. CVD risk following TSCI was also explored, with only one participant reporting being diagnosed with a CVD condition, namely HPT, since being discharged from hospital. The findings presented an analysis of the challenges encountered by participants as they attempted to engage in physical activities after being reintegrated back into their communities. Additional commentary was obtained from participants who had been reintegrated back into their communities for a longer period than the participants from

the original cohort and could speak from a fuller lived experience as it pertained to their ability to be physically active.

The identification of CVD prevention programmes are described and discussed in the Chapter 6.



CHAPTER 6

SCOPING REVIEW

6.1 INTRODUCTION TO THE CHAPTER

In the final phase of the study, literature regarding CVD prevention among the SCI adult population was reviewed in the form of a scoping review. The chapter starts by providing an overview of scoping review methodology followed by the results of the scoping review and the chapter is drawn to a close with a discussion on the proposed CVD prevention strategy for SCI individuals in the South African context.

6.2 OVERVIEW OF THE SCOPING REVIEW

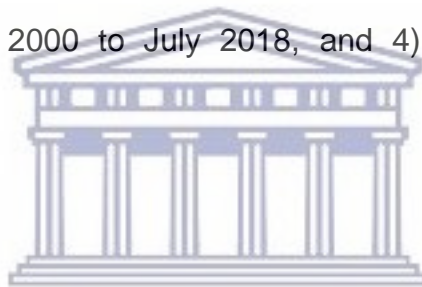
Scoping reviews are becoming an increasingly popular approach for synthesising health research evidence (Pham et al., 2014; Daudt, van Mossel & Scott, 2013; Arksey & O'Malley, 2005). While being a relatively new approach for which there is not yet a universal study definition or definitive procedure (Daudt et al., 2013), scoping reviews provide researchers with a tool to assess relevant and qualified results about the knowledge available on a particular topic (Arksey & O'Malley, 2005). The research question underpinning the study's scoping review was, "Can CVD onset in the SCI population be reduced in the SCI population?" In the present study, the phased approach of Arksey and O'Malley (2005) was utilised in order to meet the main aim of this phase: to identify cardiovascular disease prevention strategies for individuals with a spinal cord injury. This was done to map existing literature identifying possible prevention strategies that can be utilised for individuals

with SCI within the South African context. The specific inclusion criteria, search strategy and results are delineated in the next section.

6.3 METHODOLOGY

6.3.1 Inclusion criteria

The literature included in the scoping review met the following criteria: 1) the target participants had to have had a spinal cord injury, which could be either traumatic and non-traumatic injuries; 2) the age of the target participants was at least 18 years old, or the target participants included subjects aged 18 years and above; 3) publication period was from January 2000 to July 2018, and 4) manuscripts published in English.



6.3.2 Search strategy

The search strategy was developed in order to identify CVD prevention strategies among the SCI adult population. The initial search was initiated in August 2018 in multiple databases. The keywords included in the search were spinal cord injury, traumatic spinal cord injury, cardiovascular disease prevention, strategies, cardiovascular prevention programmes and chronic disease prevention. The search was performed in the following databases: MEDLINE, CINAHL, Academic Search Premier, HEALTH SEARCH: Nursing/Academics Edition and MasterFILE Premier. Additional databases, namely ERIC, PsycARTICLES and SocINDEX, were also searched but yielded no results. The aforementioned databases were chosen as they were comprehensive and identified a broad range of sources of information on SCI and CVD prevention strategies. Reference lists of few randomly selected

studies were also searched. Additional articles were also hand-searched from key journals to identify titles that might have been missed in the databases and reference lists.

6.3.3 Data extraction and assessment

Literature identified in this process were described according to specific criteria including the year of publication, study design, study location, prevention strategies utilised, main results and research implications.

6.4 RESULTS

The overview of the types of the articles selected is provided in Table 6.1 highlighting the author(s), year of the study, study design, aim of the study, study location, prevention strategies, main results and the research implications. In the electronic search 55 studies from the selected databases were identified: Academic Search Premier= 10, CINAHL= 32, Health Sources: Nursing/ academic edition = 4, Master File Premier= 1, MEDLINE = 8 and additional 4 articles from a manual search yielding a total of 59 articles. Reliability of the aforementioned search findings was crosschecked after consultation with the university librarian who assisted in setting up the parameters for the scoping review. She conducted an independent search using the same key words and we were able to compare the independent searches and obtained identical results. After title/abstract screening, 28 articles were excluded, as they were not related to programmes addressing CVD prevention after SCI and an additional 3 were excluded because they were duplicates. The researcher then retrieved and reviewed 28 abstracts. Out of these 28 abstracts, the researcher excluded 9 due to relevance, as they were not deemed relevant for

inclusion based on content, subjects and overall aim. After reviewing the abstracts, 19 full text articles were included. Out of these 19 full text articles, 9 were included in the final analysis. Figure 6.1 presents the flow chart of included studies in the scoping.

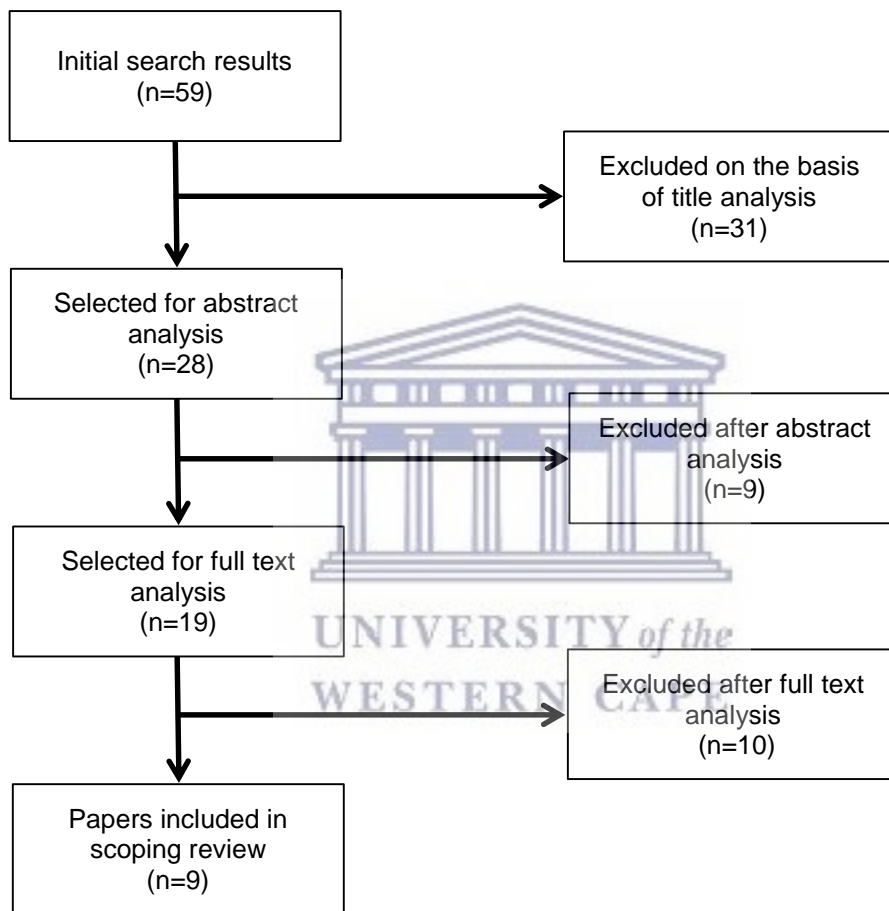


Figure 6.1 Flow diagram of search strategy and study selection process

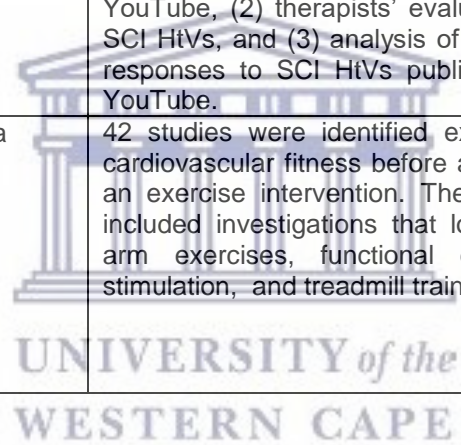
Table 6.1 Studies addressing cardiovascular disease prevention based on framework described by Arksey & O'Malley, (2005)

AUTHORS & YEAR	STUDY DESIGN	STUDY AIM	STUDY LOCATION	INTERVENTIONS	MAIN RESULTS AND RESEARCH IMPLICATIONS
Crane, Hoffman, & Reyes, 2017	A prospective cohort study	To describe the initial benefits of a structured group exercise program on exercise frequency and intensity, perceived health, pain, mood, and television watching habits.	United States	Participants with SCI took part in a voluntarily free, bi-weekly physiotherapy lead group exercise class over 3 month period.	Structured, small group exercise after SCI was seen to improve regular exercise participation and overall health state, mood, pain and hours spent watching television. The researchers suggest additional research to determine if the improvements seen can be maintained after completing their programme and across all neurological levels of SCI.
Kooijmans et al., 2017	Assessor-blinded randomised controlled trial	The Healthy Active Behavioral Intervention in SCI (HABITS) study's main aim was to evaluate the effectiveness of a structured self-management intervention among inactive persons with long-term SCI to promote an active lifestyle.	Netherlands	Participants were randomised into two groups. One group was a 16-week self-management intervention which consisted of group meetings, individual counseling and received a book. The other group was a control group that only received information about living an active lifestyle by one group meeting and a received the same book as the other group.	Structured 16-week self-management intervention was not seen to be effective to change the behaviour of individuals with SCI towards living a more active lifestyle. It was also not seen to improve perceived behavioral control, attitudes and stages of change of individuals.
Bigford et al., 2017	A prospective case series	Analysing the effects of a comprehensive lifestyle intervention program in three patients with chronic paraplegia having	United Sates	Three individuals underwent an intense 6-month programme of circuit resistance exercise, nutrition using a Mediterranean diet and behavioral support, followed by a 6-month extension (maintenance) phase	All participants achieved the goal for 7% reduction of body mass and maintained the loss. Improvements were observed in 2/3 subjects for HOMA-IR and high-density lipoprotein cholesterol. All participants improved their risk for plasma triglycerides.

		major risks for the cardiometabolic syndrome (CMS)		involving minimal support. The primary goal was a 7% reduction of body mass. Other outcomes analysed insulin resistance using the HOMA-IR model, and plasma levels of fasting triglycerides and high-density lipoprotein cholesterol.	They concluded that a lifestyle intervention programme results in clinically significant loss of body mass and effectively reduced component risks for CMS and diabetes. These results were for the most part maintained after 6-months of minimal supervision.
Totosy de Zepetnek, et al., 2015	Randomised controlled trial	To evaluate adults with spinal cord injury (SCI) in a 16-week exercise programme following the physical activity guidelines (PAG).	Canada	Participants were randomly assigned to either a PAG training group (n=12) or active control group (n=11). The PAG training regime took place twice a week and involved 20 minutes of moderate-vigorous aerobic exercise and upper-body strengthening exercises. The control group were asked to maintain their existing physical activity levels and did not receive any additional guidance on training intensity.	There was no significant improvement in markers for CVD seen in individuals who took part in 16-week programme using the PAG. It is however suggested that the PAG still be promoted among the SCI population to increase physical fitness and maintain body composition.
Myers, Gopalan, Shahoumian, & Kiratli, 2012	Pilot evaluation	To determine if a multidisciplinary team risk management programme influences CVD risk in persons with SCI over a 2-year period.	United States	Participants, who had SCI, took part in a 2-year risk intervention programme pilot. The intervention included frequent telephone calls by a case manager and face-to-face visits by a physiotherapist, dietitian, and exercise physiologist to participant's homes. Data was collected at 6-month intervals and included information pertaining to glucose and lipids readings, dietary intake, physical activity patterns, and exercise capacity.	There was modest changes in some of the risk markers of CVD because of the multidisciplinary team risk management programme to persons with SCI. There were however some challenges when compared to ambulatory persons, and more intensive risk intervention is proposed to achieve an appreciable reduction in CVD risk in the SCI population.
Nooijen et al., 2012	A prospective cohort study	To examine the longitudinal relationship between unbiasedly estimated	Netherlands	Data was collected from participants with a recent SCI at the three different points in time i.e. the beginning of their active rehabilitation, when they were	An expansion in physical activity level was essentially identified with an expansion in VO ₂ peak and POpeak, and an increase in physical activity level positively influenced the

		ordinary physical movement level, and physical wellness and lipid profile in people with a recent SCI.		discharged from inpatient rehabilitation (3 months later), and 1 year after being discharged from inpatient rehabilitation. Physical activity level (duration of dynamic activities as % of 24 h) was measured with an accelerometry-based activity monitor. Regarding physical fitness, peak oxygen uptake (VO ₂ peak) and peak power output (POpeak) were determined with a maximal wheelchair exercise test, and upper extremity muscle strength was measured with a handheld dynamometer. Fasting blood samples were taken to determine the lipid profile.	lipid profile. A nonsignificant connection was found with muscle strength. Everyday physical activity appears to have role in the wellness and wellbeing of people with an recent SCI. An expansion in physical activity level was related with an expansion in physical fitness and with a lower risk of CVD.
Thomas et al., 2011	Randomised controlled trial pilot study	To investigate changes in exercise behavior of individuals with a spinal cord injury (SCI) after interacting with knowledgeable health care professionals and receiving a tailored home programme of physical activity.	United States	Participants were randomly assigned to 1 of 2 intervention groups one being a basic intervention group and the other being an enhanced intervention group. Data were collected by 4 separate assessments occurring at 3-month intervals. The participants documented their participation via self-report, and each individual's readiness to change his/her physical activity behaviors was evaluated via responses to a questionnaire based on the 5 stages in the transtheoretical model of health behavior change.	Provision of a home exercise programme using a brochure and a DVD/videotape appears to be an effective strategy for promoting increased physical activity in sedentary persons with SCI. Both intervention groups fundamentally expanded their number of physical activity minutes per week and moved to higher SOC amid the period from Time 1 to Time 2. As the study progressed, both intervention groups continued to demonstrate expanded quantities of physical activity minutes per week, and in addition an expansion in the quantity of participants that were in the activity and support phases of the Transtheoretical Model. Ramifications of the study recommend that home programmes in which knowledgeable health care professional encouragement is provided may positively change exercise behaviors and real cooperation in physical activity by people with

					a SCI.
Libin et al., 2011	Mixed method descriptive study	The purpose of study was to describe a preliminary analysis of SCI-specific educational videos posted to YouTube.	United States	Quantitative and qualitative data was obtained from participants with SCI looking at aspects of SCI-specific educational videos generally available on YouTube, as well as specifically developed How to Videos (HtVs). 3 aspects were focused on for the SCI- focused educational videos: (1) content analysis of SCI-specific educational videos posted on YouTube, (2) therapists' evaluation of SCI HtVs, and (3) analysis of viewers' responses to SCI HtVs published on YouTube.	A peer-to-peer knowledge exchange approach advances self-management of wellbeing and social capacity after an individual has been affected by a traumatic accident like SCI. A library or archive of on-line HtVs accessible free restoration programmes, and on-line discussions will give an assortment of tools to people with a SCI for adapting better approaches to do daily exercise. The HtV in interactive media based instruction for health care needs services needs to advance a new methodology based on a more individualized, disability-specific approach while employing videos as learning tools.
Warburton, Eng, Krassiouko & Sproule, 2007	Systematic review	The review looked at literature, regarding CVD risk in SCI and the effectiveness of different exercise rehabilitation programmes	Canada	42 studies were identified examining cardiovascular fitness before and after an exercise intervention. The studies included investigations that looked at arm exercises, functional electrical stimulation, and treadmill training.	The preliminary evidence suggests that various exercise modalities lead to improvements in several CVD markers i.e. lipid lipoprotein profiles, cardiovascular fitness and glucose homeostasis in the SCI population studied. Exercise is proposed as a useful tool for reducing the risk for CVD and multiple comorbidities (such as type 2 diabetes, hypertension, obesity) in SCI.



6.5 DISCUSSION

The strategies identified in this phase of the study were mostly related to physical activity/exercise and self-management tools to prevent and manage CVD.

Physical activity and exercise

Six studies (Crane et al., 2017; Bigford et al., 2017; Totosy de Zepetnek et al., 2015; Nooijen et al., 2012; Myers et al., 2012; Warburton et al., 2007) were selected which identified programmes and/or strategies that promoted physical activity in SCI population with the aim of reducing CVD risk. As indicated by Crane et al. (2017), people with SCI, participating in an organised, small group exercise class exhibited a greater interest in standard exercise and expanding exercise power. The points of interest extend across over various zones of wellbeing. As the level of physical activity was seen to be a strong determinant of glucose versatility, self-sufficient of the level of neurological disability, exploring strategies to propel participation in physical activity will be essential for all individuals with SCI. Bigford et al. (2017) investigated the effects of a comprehensive lifestyle intervention programme in three patients with chronic SCI. The therapeutic lifestyle intervention involved behavioural support, circuit resistance training, and a calorie-restrictive Mediterranean-style diet. Their findings reported substantial weight loss of $\geq 7\%$, and reported effectively reduced component risks for CMS. Of interest was that these results appear to be maintained following an additional six months of minimal contact. Bigford et al. (2017) suggest a larger sample population to confirm these findings and determine the extent to which the lifestyle intervention would be optimal for persons with SCI. Nooijen et al. (2012) detailed constructive findings when looking at the relationship

between movement level and lipid profile which proposed that people with a SCI who are more physically dynamic have less danger of CVD. They recommended that given the health-related advantages of a higher everyday physical activity level, that more consideration ought to be paid to physical activity level during rehabilitation, with the objective of advancing an active way of life after discharge from the rehabilitation centre. They further suggested that everyday physical activity might be advanced by means of behaviour-oriented interventions. According to Myers et al. (2012), modest but significant changes in CVD risk can be accomplished by a multidisciplinary team risk reduction programme in people with SCI. Such programmes present a bigger number of difficulties than those in ambulatory subjects, and accomplishing the objectives suggested may require novel or inventive methodologies as well as more intensive risk intervention with the end goal to viably lessen CVD chance in this populace.



Contrary to the above studies, Totosy de Zepetnek et al's (2015) RCT to determine the effects of implementing the PAG on CVD risk factors found it not to be as beneficial to improve many markers of CVD risk. The investigation observed no training-related changes in any customary CVD risk factors, blood biomarkers, or in the novel CVD risk components of regional blood vessel firmness or capacity, proposing that four months of adherence to the PAG does not give an adequate upgrade to actuate these changes. They suggested that it was conceivable that as a result of the utilisation of arm-only exercise and the low initial fitness levels that the absolute intensity in the PAG group was not adequate to evoke more far-reaching changes. The analysts featured that notwithstanding their discoveries, PAG was developed considering fitness benefits and have appeared to enhance muscle

strength and peak aerobic capacity (peak oxygen consumption). While they should keep on being elevated as a way to increment physical fitness, changes might be required to initiate changes to CVD profile. Furthermore, Warburton et al. (2007) in their systematic review more than ten years ago, concluded that the relationship between increasing physical activity and health status of SCI had not been evaluated adequately and that further long-term follow-up investigations are required to determine whether training-induced changes in risk factors for CVD translate directly into a reduced incidence of CVD and premature mortality in persons with SCI. On a positive note, they highlighted that preliminary evidence indicated that various exercise modalities might improve cardiovascular fitness and reduce certain CVD markers in persons with SCI. Specifically it was shown to reduce multiple comorbidities (such as type 2 diabetes, hypertension, obesity) and the risk for CVD in the SCI population.



Self-management strategies

Three studies (Kooijmans et al., 2017; Libin et al., 2011; Thomas et al., 2011) were identified which looked at various self management tools to lower the risk of developing CVD. Kooijmans et al. (2017) evaluated the effectiveness of a self-administered intervention to advance an active way of life in people with long-term spinal cord injury called the Healthy Active Behavioural Intervention in SCI (HABITS) Randomised Clinical Trial. The researchers discovered that an organised 16-week self-administered intervention was not successful to change conduct toward a more active way of life and to enhance apparent social control, phases of change, and state of mind in people with a long-term SCI.

Contrary to this Libin et al. (2011) observed YouTube to be a valuable apparatus in teaching individuals with SCI on the making more astute health decisions. Libin et al. (2011) discovered that a peer-to-peer knowledge mobilisation approach advanced self-management of health and social capacity after an individual has been affected by a SCI. Furthermore, they highlighted that the "How to Videos" (HtV) worldview in multimedia-based education for healthcare services needs to advance a new methodology based on a more individualised, disability-specific approach while employing videos as learning tools. They found that video demonstrations increase understanding of procedural skills, of which HtVs are a type, without specific regard to learner literacy. According to Thomas et al. (2011), a home exercise programme by means of a brochure and a DVD/videotape with exercises specifically appears to be an effective strategy for promoting increased physical activity by sedentary persons with SCI. Participants were randomly assigned to one of two intervention groups one being a basic intervention group and the other being an enhanced intervention group. Positive results were seen in both intervention groups with significantly increased number of physical activity minutes per week. Furthermore, as the study progressed, both intervention groups continued to show increased numbers of physical activity minutes per week, as well as an increase in the number of participants that were in the action and maintenance stages of the transtheoretical model used as the theoretical framework in their study. Despite the small sample size and inclusion of individuals with a variety of levels of SCI, the findings offer support to the premise that this population will respond in a positive manner to a prescribed home exercise program when advised by knowledgeable health care providers.

6.6 SUMMARY OF THE CHAPTER

Physical activity has been shown to have numerous health benefits of which reducing the risk of CVD is one. Engaging in physical activity, whether it be structured, unstructured or through a home based exercise activities can play a major role in combating the onset of CVD. The duration, frequency and intensity is still not clearly defined. Other tools used in reducing the onset of CVD were seen to be self management strategies of which contrayer views were seen both for and against their use.

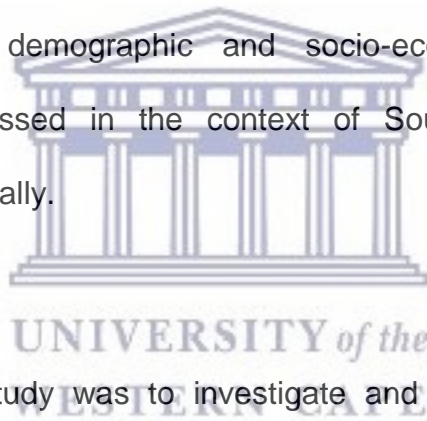


CHAPTER 7

DISCUSSION

7.1 INTRODUCTION TO THE CHAPTER

This chapter provides an integrated discussion of the results of the study. Where appropriate, the researcher compares the study's findings to existing relevant local and international literature. Given the paucity of scientific evidence on TSCI in South Africa, specifically around the variables investigated in the study, reference will be made to available evidence on CVD risk seen in the international TSCI population. Data pertaining to the demographic and socio-economic characteristics of participants will be discussed in the context of South Africa and the Cape Metropolitan region specifically.



The overall aim of this study was to investigate and explore the need for the implementation of CVD prevention programmes after sustaining a TSCI in a regional South African population. This research project provides evidence with regards to the risk profile of individuals with TSCI for CVD and highlights the importance of CVD prevention programmes for individuals with a TSCI.

7.2 EPIDEMIOLOGICAL PROFILE OF STUDY SAMPLE


Demographics

Up until about five years ago, Africa was seen to produce scanty data pertaining to TSCI and affected individuals. This has, however, changed in recent years with an

upsurge of African based TSCI studies; the current study adds to the growing number of studies emerging on the African continent focusing on individuals coping with TSCI. The current study was, in part, an observational study of a larger project's incidence cohort specifically conducted at the only hospital-based specialised ASCI unit in the Cape Metropolitan Area, an urban setting in the Western Province of South Africa. Overall, 132 individuals sustained a TSCI during the initial phase of the study period and were subsequently admitted to the GSH ASCI unit. Of these 132 individuals, 108 consented to being included in the study.

Evident from the findings of the study was a high propensity for young males who sustained a TSCI in the Cape Metropolitan area. The study reported a male/female ratio of 6.2:1 and further found that males presented with a lower mean age (33.29 years) compared to females (37.66 years). Global evidence also indicates that a greater propensity to males sustaining a TSCI compared to females (Kumar et al., 2018; WHO, 2013; DeVivo, 2010). Recently Kumar et al. (2018) reported that males were more commonly affected by TSCI, with an average male/female ratio of 3.37:1 worldwide through all WHO regions and income levels. The current study's data highlighted that South African males were almost double the international male/female ratio and poses the question, "Why are males, in the current context at a greater risk for sustaining a TSCI?" Interestingly, a high male/female ratio was also reported in a developing country in South America, namely Brazil, with a ratio of 7.35:1 (Santos et al., 2009). Other African studies reported varying ratios with Nigeria reporting a 2:1 ratio of males to females (Olasode et al., 2006), Zimbabwe reporting a high 12.4:1 ratio (Levy et al., 1998), Botswana reporting a 2.4:1 ratio (Löfvenmark et al., 2015) and Tanzania reporting a ratio of 3.5:1 (Moshi et al., 2017).

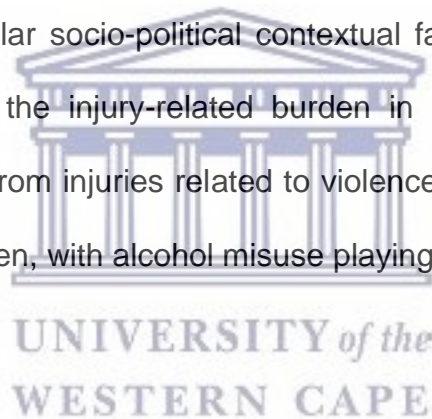
According to Kumar et al. (2018), the overall ratio of males/females was seen to be higher in LMIC compared to HIC, and highlights concerns about the resource allocation available for this vulnerable population group in a developing country like South Africa. This is placed in context in another South African study (Norman, Matzopoulos, Groenewald, & Bradshaw, 2007) that reported that males in Africa have the highest injury-related mortality rates worldwide. They posit that due to limited reliable statistics, health and development impacts of injuries remain unknown. Global burden of disease assessments, however, have highlighted its part in premature deaths and disability among young male adults, with injuries estimated to account for 9% of deaths and 12% of the burden of disease worldwide. Further highlighting this neglected health problem in developing countries.



This study further confirms previous South African studies findings of the high rates of young males sustaining a TSCI. Maclachlan (2012) reported the gender distribution for her TSCI study sample, clearly illustrating a much higher proportion of males (91%) compared to females (9%); Hart and Williams (1994) reported 80% of their study sample as male, with males between 15 and 40 years of age making up the majority of the patients in their study. More recently, Sothmann et al.'s (2015) 11-year retrospective study at the same spinal cord unit as this study, reported patients admitted during their study period to comprise 84% (n=1 715) males and 16% (n=327) females with a male/female ratio of 5.25:1. Similar results from another South African study reported a male/female ratio of 6:4 (Pefile et al., 2018).

The researcher believes that young males in South Africa are at an even great risk for sustaining a TSCI given the fact that they are involved in more high-risk

behaviour. This is supported by the etiology of TSCI reported by the study cohort with TSCI seen to be more common in the age category 20 – 29 years old and was significantly more likely due to assault when compared to the other age categories. Given this and the considerable proportion of males sustaining TSCI, further investigation, elucidation and planning both at a community and government level are necessary for the purposes of prevention, early intervention and planning for their required appropriate rehabilitation services. In particular, the higher propensity for males sustaining TSCI necessitates additional review to investigate reasons contributing to this higher risk profile. Previous studies have highlighted that males engaged in more risky behavior. Norman, Matzopoulos, Groenewald and Bradsaw (2007) also identify particular socio-political contextual factors playing a role in the magnitude and impact of the injury-related burden in South Africa indicating an exceptionally high burden from injuries related to violence and road traffic accidents, more so among younger men, with alcohol misuse playing a major contributing role.



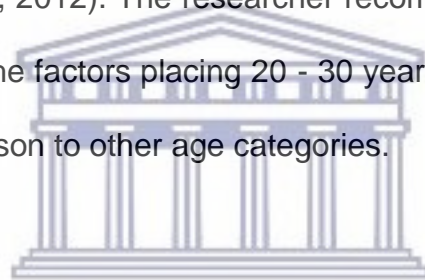
As indicated, this study's assertion that young males are more likely to sustain a TSCI is closely aligned to trends witnessed in both developed and developing countries. These findings highlighted the need to identify risk factors that place this specific population at greater risk for TSCI for the purpose of developing prevention strategies to curtail further high incidence rates in this population group and for resource allocation. Given South Africa's dominant patriarchal society construction, injury to males leads to major economic strain on households where they are the main breadwinners, and, sometimes, the only breadwinners. This requires concerted focus to decrease the impact felt by families of the injured individuals. Furthermore, this would be especially useful to understand as the disabled population, of which the

TSCI population is part, puts a significant strain on the social welfare system with many of patients accessing governmental benefits when not being able to work and earn a living to support their families following their injury.

The WHO (2013) postulated that age and sex influenced the etiology of TSCI throughout the life cycle. International trends indicate that the highest incidence of TSCI was seen in younger patients. Data from one study in the USA indicated that the highest incidence of TSCI was found in patients in their late teens and early twenties (DeVivo, 2012); while another systematic review study concluded that the majority of patients with TSCI were young men in their thirties (Wyndaele & Wyndaele, 2006). Other studies, both from China, reported a mean age of 41.7 years old in Beijing (Li et al., 2011), and 46 years old in Tianjin (Ning et al., 2011) respectively, which was higher than other international studies. Studies conducted on the Africa continent reported similar trends to Wyndaele & Wyndaele (2006). Two studies in Nigeria reported that the average age of patients sustaining a TSCI was 37 years old (Solagberu, 2002) and 30 years old (Olasode et al., 2006) respectively. Other African countries reported the average age to be 36 years old in Senegal (Seye et al., 1993), 30 years old in Sierra Leone (Gosselin & Coppotelli, 2005), and 28 years old in an older South African study (Hart & Williams, 1994). Löfvenmark et al. (2015) reported the age of TSCI individuals in Botswana to range from 4 to 81 years old, with 80% of the cohort being ≤ 45 years old. In Tanzania, Moshi et al. (2017) reported a mean age of 39.1 years old (SD= 16.3) in their TSCI cohort. Recently a study in South Africa in the province of Kwazulu Natal, reported the mean age for TSCI as 33.11 years old (SD 11.85). Some African studies grouped age categories and reported the average age to be between 30 – 40 years old in Nigeria

(Obalum et al., 2009), 20 – 40 years old in Zimbabwe (Levy et al., 1998) and 21 – 30 years old in South Africa (Sothmann et al., 2015).

These individuals (young, males) are often in the prime of their lives and a serious injury would likely result in considerable economic and social consequences to them as individuals, their families and communities at large. The study's findings related to age are considerably lower than most international trends, even compared to other developing countries on the African continent. Interestingly, the results from the study are closely aligned to data emanating from a study conducted in the USA, a developed country (DeVivo, 2012). The researcher recommends that further analysis be conducted to examine the factors placing 20 - 30 year age group at higher risk for sustaining TSCI in comparison to other age categories.



The study reported the main etiology of TSCI to be as a result of assault, RTA and falls. Assault was the most common cause of injury (58.33%). The majority of assault cases were males with a mean age was 29.92 years old, while females accounted for only 11.11% of the cases with a similar mean age of 28.29 years old. Wood (2006) reported that South Africa had the worst income inequality and the highest rate of homicide of the 63 countries he studied. He analysed the relationship between socio-economic inequalities and violence and found that income inequality, low economic development, and high levels of gender inequity are strong positive predictors of rates of violence, including homicides and major assaults. Furthermore, unemployment, particularly related to male youths, was the most consistent correlate of homicides and major assaults (Gawryszewski & Costa, 2005; Wilkinson, Kawachi,

& Kennedy, 1998). This is of major concern as the current study reported males to be significantly more likely to be injured as a result of assault and therefore additional research is suggested to curtail the resulting high incidence of TSCI seen because of interpersonal violence.

The link can be made that poverty leads to higher rates of interpersonal violence as this has been seen to occur in more poverty stricken communities compared to affluent ones. Over a third of South Africa's population is unemployed (The Presidency, 2008). The resulting poverty leads to numerous social and psychological challenges. Where there is significant inequality, as is the case in South Africa, increasing anger and frustration often lead to violence (Wilkinson et al., 1998). Ten years later, Norman et al. (2007) continued to highlight the high propensity of violence in South Africa and linked its high occurrence to the legacy of the apartheid past. The researchers further purported that high unemployment, gender inequality, income inequality, poverty, family breakdown and poor rule of law have contributed to this climate of violence. There is an escalation of these dynamics in urban areas (informal settlements) typified by poor community cohesion, dense populations, rapid urbanisation, and inadequate housing infrastructure (Ratele, 2008). As the majority of individuals from the incidence cohort resided in communities classified as informal dwellings on the Cape Flats, the researcher postulates that the poverty seen in these communities places considerable strain on males in these communities who, as seen in the study, were often unemployed and could therefore not provide for their families. This is noteworthy in the South African context given the high percentage of individuals with TSCI due to assault and requires comprehensive research to

ascertain the contributing factors leading to high number of interpersonal violence perpetrated by males.

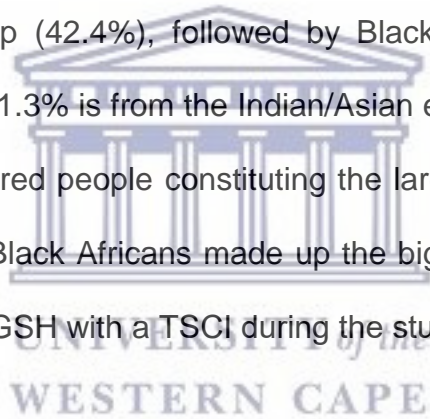
Of interest was that the Americas are highlighted as the WHO region with the highest proportion of violence-related TSCI (14%) with Africa coming in second (12%). Interest to note is that this figure has reported to be on the decline from 21% in the 1990s to 12% since 2000 (DeVivo, 2010). Country-specific data, such as from Afghanistan, ravaged by war, reported considerably high incidents of TSCI with 60% of cases being attributed to violence more than a decade ago (Deconinck, 2003). Several other older South African studies also reported “violence” as the main causation of TSCI (Velmahos et al., 1995; Hart & Williams, 1994). Specifically, Hart and Williams (1994) found violence to be present in 56% of all cases reviewed, followed by motor vehicle accidents (25%), and falls from heights (2.5%). Velmahos et al. (1995) reported that acts of violence accounted for 61% of the cases, followed by traffic accidents (30%). Twenty years later, Joseph et al. (2015) presented similar findings indicating assault as the main cause of TSCI (59.3%), highlighting a unique problem in South Africa. This was contrary to recent conclusions of another South African study at GSH by Sothmann et al. (2015) who found the most prevalent cause of acute SCI over an 11-year period to be motor vehicle accidents (MVAs), which accounted for 44.6% of all injuries (n=910). Falls accounted for 15.5% of all injuries (n=316) and gunshot wounds (GSWs) for 14.4% (n=294). Their findings positioned the causes in South Africa to be similar to international trends. However, their study was a retrospective study with no geographic limitations on participant pre-admission destination and therefore cannot be directly compared to the current study. Most sources of error due to confounding and bias are more commonly seen in

retrospective studies compared to prospective studies. The strength of the current study, was in its prospective longitudinal design, which has been seen to have fewer potential sources of bias and confounding than retrospective studies (Euser, Zoccali, Jager, & Dekker, 2009).

The second main cause of TSCI in the study was RTA (25.92%). For males the mean age was seen to be 38.43 years old (SD=12.24) and accounted for 82.14% (n=23) of the RTA cases. Females were seen to be older with a mean age of 43.2 years old (SD=22.06). Researchers have put South Africa's road traffic mortality rate at 39.7 per 100 000 and further promulgated that it was 26% higher than the aggregate for the African region and almost double that of the global rate (Norman et al., 2007; Matzopoulos et al., 2004). The high rates of RTA is evident in a local study conducted by Sothmann et al. (2015), identifying this as the leading cause of TSCI. Local evidence indicates a steady increase in traffic mortality since 2003 in Johannesburg, Cape Town, and Pretoria (Donson, 2008). It was further reported that half (56.7%) of road accident deaths occurred in people aged between 20 and 44 years old, with the 30 – 39 years age group being most at risk (Donson, 2008; Prinsloo, 2007). Three-quarters of traffic deaths involved males (Norman et al., 2007). The main contributors to these high rates of traffic deaths and injuries were reported as excessive speeding, alcohol misuse, inadequate accommodation of pedestrians and other non-motorized road users (Ribbens, Everitt, & Noah, 2008; Sukhai, & Seedat, 2008; Matzopoulos, du Toit N, & van As, 2008; Sukhai, Noah, & Prinsloo, 2004). The mean age in the study was shown as 39.29 years old, which corroborates Donson (2008) and Prinsloo's (2007) findings of this age group being most at risk.

Falls was cited as the third main reason for TSCI in the study (12.04%). Kumar et al. (2018) recently reported falls as the second main cause of TSCI globally. Five years ago, the WHO (2013) also cited falls as the second cause of TSCI when looking at international etiological data. The incident rates differed across regions with a range of 14 to 40% of cases, with Africa reporting the lowest incidence. Contrary to this, in a recent study, Moshi et al. (2017) reported the main cause of injury as falls in Tanzania with it being responsible for nearly 50% of the cases (48.8%, n=104). Two Japanese studies conducted almost two decades ago reported higher than average proportion of falls; this was attributed to the aged population with 29.7% of people being aged 60 years and over (Shingu et al., 1995; Ide et al., 1993). This might be an indication of the future global trend given the increase in the older population expected to be seen in upcoming years. Pakistan and Bangladesh reported some of the highest incident rates of falls with 82% and 63% respectively, particularly off trees and rooftops in Pakistan (Raja, Viohra, & Ahmed, 2001) and trees in Bangladesh (Hoque et al., 1999). The Fiji Islands also reported a high incidence of falls (39%, Maharaj, 1996). A study in Nepal reported falling from trees (40%) and from buildings (28%) as the main causation (Lakhey, Jha, Shrestha, & Niraula, 2005). The risk of injury as a result of falls is expected to become a growing point of concern given the recent STATSSA report (2017) indicating that the proportion of elderly (60 years and older) in South Africa is growing, reaching 8,1 % in 2017. According to the estimates, there are 4,6 million people in South Africa over the age of 60. More research is necessary to address this growing concern as falls have been seen to be more common in the older population both in the current study and in other studies.

Another noteworthy demographic characteristic examined in the study was race. The data indicated that a majority of patients in the cohort were Black African (52.78%, n=57), followed closely by the Coloured patients (42.59%, n=46). Individuals from the White race group (3.7%, n=4) and “other” (0.93%) were in the minority. This does not fully mimic the relative distributions of these racial grouping in the Cape Metropolitan region or Western Cape province. While there is little scientific evidence assessing the role of race in the incidence of TSCI, this variable is a notable element in a South African narrative. The race distribution of the population in Cape Town, as a direct result of Apartheid, is important when considering the demographic profile of the cohort. Within the Cape Metropolitan region, Coloured people (mixed-race origin) constitute the largest group (42.4%), followed by Black Africans (38.6%), Whites (15.7%) and the remaining 1.3% is from the Indian/Asian ethnic group² (Posel, 2001). Interestingly, despite Coloured people constituting the largest racial group within the region, the data indicates Black Africans made up the biggest proportion of patients in the cohort presenting to GSH with a TSCI during the study’s time period.



Violence and injuries are the second leading cause of death and lost disability-adjusted life years in South Africa, second only to HIV/AIDS (Norman et al., 2007). Furthermore, South Africa has twice the global average of overall injury death rates (157.8 per 100 000 population) (Matzopoulos, Norman, & Bradshaw, 2004). The authors also reported interpersonal violence to be the leading cause of injury in

² South African’s Population Registration Act of 1950 required that each citizen be issued an identity document stating his or her race as White, Native (African) or Coloured. “Coloured” was used to define people who were neither white nor “native”, a catchall category primarily for people of mixed race. A category for Indians (that is, South Asians from the former British India, and their descendants) was later added as a separate classification as they were seen as having “no historical right to the country” (Posel, 2001).

South Africa. The findings of this study is examined and interpreted under this lens, and takes into account the legacy of Apartheid and the subsequent displacement of various race groups into demarcated geographical areas. The enormous impact of these actions has resulted in disrupted communities, high crime rates and poverty (Pinnock, 2016).

This was evident in this study with increased TSCI incidence rates in Black African and Coloured males as a result of interpersonal violence. The disproportionate role young men in South Africa play as perpetrators and victims of violence bring this on. The highest homicide victimisation rates in the country are seen in men aged 15 – 29 years old (184 per 100 000) (Norman et al., 2007) and in Cape Town townships rates are more than twice this number (Groenewald et al., 2008). Male deaths due to homicide outnumber women by more than seven times. Although most homicide victims are Black Africans, the highest rates are reported in Coloured men and women (Abrahams et al., 2009; Altbeker, 2007). The highest proportion of participants in the cohort resided in Mitchells Plain, Khayelitsha and Nyanga area. These areas are described as some of "Apartheid's dumping ground" from the 1960s where these areas became home to "non-white" people displaced from their established communities in terms of the Apartheid government's Group Areas Act.

Unemployment appeared to be a salient factor. The unemployment rate within the Cape Town municipality from STATSSA Quarterly Labour Force Survey (2017) was reported as 21.5%. The Housing Development Agency (2013) reported the staggeringly high unemployment rates of 41% in informal settlements within the

Western Cape. The catchment area for the study included several informal settlements, experiencing high rates of unemployment. This was seen in the study cohort where a large portion of participants was unemployed (56.48%). The combination of crime and unemployment has been reported to have statistically significant correlations in the South African context (Seedat et al., 2009).

In summary, the international trend has seen the main causation of TSCI to be from RTA but the present study reported assault as the main cause of injury specifically in young males. Furthermore, the strong association between poverty and inequality in South Africa is widely reported and has directly contributed toward South Africa's burden of violence and injury (Seedat et al., 2009). While the impact of these dynamics cannot be denied, the interconnectivity to other key drivers is also important to consider; factors such as alcohol abuse, dominant patriarchal constructions of masculinity, the intergenerational recycling of violence, and the proliferation of firearms. Important to note is the limitation of the study in identifying the types of violence perpetrated against individuals. Further investigation is needed to assist in the reduction of interpersonal violence and RTA seen in the South African context as to assist in the curtailing of the TSCI in the young male population and the development of specific prevention strategies in this population group.

Injury Classifications

The study cited the cervical part of the spinal cord as the most common site of injury (50.93%) for both males and females, followed by thoracic (39.81%) and lumbar area (9.26%). Two separate regional studies in China, in Guangdong (Yang et al., 2008)

and Tianjin (Ning et al., 2011) reported similar findings. The increase in cervical injuries has been previously noted in Canada (Couris et al., 2010). Studies in Western Norway (Hagen et al., 2010) Latvia (Nulle et al., 2017) and Estonia (Sabre et al., 2012) also cited similar patterns of injury. African studies recently, in Botswana (Löfvenmark et al., 2015) and Tanzania (Moshi et al., 2017), reported the cervical spine as the most common area injured at 59% (n=29) and 39.9% (n=81) respectively. No literature reviewed reported a variance in this injury pattern. This result has previously been attributed to the relatively poor mechanical stability of the cervical spine, which makes it more vulnerable to trauma (Yang et al., 2008). This, the researcher proposes would be the case regardless of the mechanism of injury, i.e. assault, RTA or falls.



In the current study paraplegia and tetraplegia classifications were fairly evenly distributed with 53 (49.07%) and 55 (50.93) cases respectively. This was similar to the results of studies in two other developing countries (Karacan et al., 2000; Hoque et al., 1999). On the African continent, Botswana reported a higher rate of tetraplegia compared to paraplegia (Löfvenmark et al., 2015). According to Ning et al.'s (2011) study, there were considerably higher tetraplegia classifications in their regional study in China. The number of patients with tetraplegia is consistent with global reports of 32–75% tetraplegia (Van den Berg, et al., 2010) with higher frequencies of tetraplegia classifications being reported from HIC compared to paraplegia in LMIC (Löfvenmark et al., 2015). Löfvenmark et al. (2015) proposed that it could be as a result of high pre-hospital mortality rates with cervical injuries seen in LMIC. With a fairly even distribution seen in the current study the researcher suggested that this could be due to better-trained first responder medical management seen within the

South African healthcare system and the subsequent reduction of pre-hospital mortality rates.

The severity of the TSCI in the study was 42 (38.89%) complete and 66 (61.11%) incomplete cases. These results were similar to other studies in other countries where complete impairment ranged between 31 - 42.3% (Sabre et al., 2013; Knútsdóttir et al., 2012; Hagen et al., 2010; O' Connor & Murray, 2006). Nulle et al. (2017) reported lower cases of complete impairments with only a quarter of the cohort in Latvia (26.1%).



The international trend has seen more tetraplegia classifications and this is not different to the results seen in South Africa, albeit marginally more compared to paraplegia. Few studies in developing countries reported the AIS classification of patients. The current study, however, reported on AIS classification and this adds to its strength giving more descriptive detail to the TSCI population locally and the subsequent symptom manifestation. Further investigation is needed to assist in the understanding the profile of the TSCI population across South Africa and not just in regional pockets. This would assist in the development of a national strategy to curtail the high number of TSCI seen regional.

7.3 CARDIOVASCULAR DISEASE RISK PROFILE

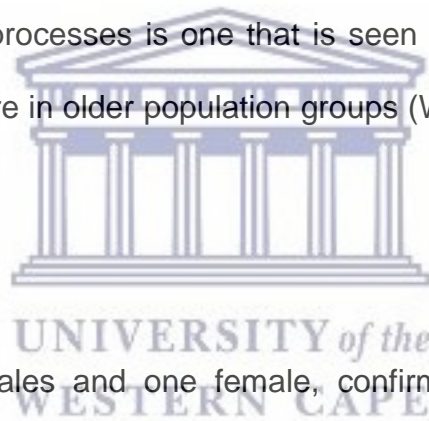
The impact of cardiovascular disease globally is now well established within the general population (Murray & Lopez, 1996). Specifically, hypertension behavioural

risk factors comprise increased body mass index (BMI) (Hu et al., 2004; Brown et al., 2000; Ford & Cooper, 1991) cigarette smoking (Niskanen et al., 2004; Halimi et al., 2002) and low physical activity (Hu et al., 2004; Haapanen et al., 1997). Males and females differ in these key behavioural risk factors. The behavioural differences suggest that opposing behavioural factors (e.g., obesity and physical activity) may narrow the gender disparity seen in hypertension (Ogden, Carroll, Kit, & Flegal, 2012; National Centre for Health Statistics [NCHS], 2012; Flegal et al., 2010; Haskell et al., 2007), while other risk behaviours (e.g., smoking) may broaden the disparity with prevalence being lower among women (Agaku, King, & Dube, 2011; Waldron 1991).

At the time of the study there was no data available for CVD risk within the TSCI community in South Africa. Given the CDL risk factors associated with aging in the normal population, and the impact that these conditions would have on the SCI population, with their moderately normal life expectancy, it becomes imperative to obtain information around the need for population specific prevention strategies to curtail the onset of CDL, specifically CVD. This paucity of data within South Africa with regards to CVD risk for TSCI individuals further highlights the possible health disadvantages faced within this vulnerable disabled population with limited specific intervention strategies available to them. The present study was the first to look at CVD risk in this regional TSCI population group in South African and adds to the ever-growing body of research for TSCI locally.

Baseline data was obtained from the TSCI incidence cohort on specific CVD risk factors. Chobanian et al. (2003) identified hypertension specifically as one of the

main causes of CVD and has been reported as one of leading causes of death in South Africans (Norman et al., 2007). Less than 10% (n=6, 5.56%) of the study cohort reported being previously diagnosed with hypertension. Males accounted for 83.33% (n=5) of the individuals diagnosed with hypertension at baseline. Follow-up semi-structured interviews and the focus group discussion also revealed low numbers of hypertension diagnosis among participants who were reintegrated back into their respective communities. This is seen by one of the participants comments when asked if they were diagnosed with any CVD, “*No, nothing*”. Given the young mean age of the TSCI cohort and the interview participants, the researcher postulates that the low rate of hypertension reported is possibly owing to the fact that the hypertension disease processes is one that is seen to develop more over time and are therefore seen more in older population groups (Wolff, Starfield, & Anderson 2002).



Three participants, two males and one female, confirmed being diagnosed with hypertension subsequent to their TSCI when contacted after one year with one participant say, “*I got high blood pressure*”. This phase of follow-up interviews were mired with considerable challenges and contacted participants only represented 15.74% (N=108) of the original incidence cohort. Owing to poor contactability of participants one year after being discharged, the calculated sample size at follow-up could not be met. The sample size for the study was 108 subjects and only 17 (15.74%) of the original subjects could be contacted one year after discharge. As the researcher couldn't discover evidence of other studies with comparable objectives that were directed on people with TSCI locally and globally, results could in any case be regarded applicable however ought to be considered with caution.

The study attempted to collect follow-up data telephonically to report on changes in CVD risk factors from the original TSCI incidence cohort one year after being discharged from hospital or rehabilitation. Data was difficult to collect in this context and was mired with considerable challenges. Only a small portion of the original cohort was “successfully reached” for follow-up interviews. Despite several attempts by the researcher to conduct the follow-up interviews telephonically, several challenges were encountered and highlighted the difficulties often encountered with longitudinal studies of this nature in a developing country like South Africa.

Bourdillon and Boyden (2012) highlighted the strength of longitudinal research as the “capacity to illuminate patterns of change in the lives of selected groups of people”. This type of data collection is seen to allow repeated, structured observations of the same cohort over time. It excludes unobservable individual characteristics that do not change over time and identifies short- and long-term patterns of change. Holland, Thomson, and Henderson (2006) purported that contemporary qualitative longitudinal research was useful in understanding what change happens, how and why the changes happens, in a specific socio-cultural context. Carduff, Murray and Kendall (2015, p.2) further highlighted one of the major advantages of qualitative longitudinal research as “the nuanced understanding of phenomena, which evolves through time.” This was particularly useful when considering the impact of illness on individuals. This methodology, while not the only implored, was deemed necessary for the current study as changes in CVD profile would only be observable over a period of time and the impact of TSCI on individuals would evolve as participants reintegrated back into their respective communities. Albeit a limited one-year follow up time period for the study, some change in the engagement of risk behaviour was

hypothesised to have occurred and important in understanding the potential development of CVD and the consequential development of specific prevention strategies for this vulnerable population group.

The use of telephonic conversations as the optimal data collection tool for this study was based on the varied geographic locations of participants' homes throughout the Cape Metropolitan area. Safety within these communities was also a factor as many of the participants were from informal settlements where crime has been positively associated within these communities. The majority of the participants resided in high crime areas and the police warned against entering them, as they could not provide a guarantee of "safety" for the researcher. It has been reported by Holt (2010), "Telephone conversations are commonly used as a mode of social interaction and are not socially or age exclusive". Carduff et al. (2015) and Holt (2010) suggested that telephone calls were a socially inclusive method of generating data and therefore deemed as a suitable manner in data collection for the study. Bernard (2002) purported it as "the most widely used survey modality in industrialised nations". Some advantages for telephonic interviews reported by Aday (1996) included i) the ability to reach geographically dispersed respondents, ii) decreased cost and travel, and iii) ability to oversee interviewers. Bernard (2002) reported that "enhanced interviewer safety" was a key strength of telephonic interviews.

The reasons for the high "drop out" rate (84.26%) for one year follow-up interviews were varied from the phone being put down when asking to speak to the participant, the cell phone number no longer being active, not answering the call despite at least

three attempts, there was no contact number available for the participant from the person contacted, incorrect telephone/cell phone numbers and participants relocated to outside of the catchment area. Despite several attempts by the researcher to gather information from the incidence cohort, the poor contact rate was possibly a unique challenge within our South African due to the migration of participants back to their original communities in other provinces. This was recently confirmed by Zuma (2018) who reported that there was a high rate of temporary migration of individuals to urban cities to seek employment in South Africa.

Holland et al. (2006) and Taylor (2009) found regular contact with participants useful in “keeping up with how people were doing” and said it improved retention. Holland and colleagues (2006) further proposed the benefit of regular contact with participants especially with transient groups for example people who were regularly in and out of hospital. The TSCI incident cohort could be considered as a transient group because of possible complication post discharge, i.e., bedsores, bladder infections and therefore contacting them prospectively could be fraught with some difficulty.

The study opted for an informal manner of telephonic engagement. This, the researcher believed, would capture the experience of the participants at the time of the phone call and would enable different themes to emerge. Holt (2010) further postulated that a further benefit to informal telephonic conversations was the fact that participants could control the privacy of the call as well as their social space. Sturges and Hanrahan (2004) also highlighted that contacted participants might feel

more comfortable discussing sensitive topics telephonically. With this methodological option though, the “drop out” rate for the study was significant and limited the meaningful insight into the lived experiences of the original incidence cohort. Some of the reported drawbacks in previous studies of telephonic interviews include poor telephone coverage, decreased response rates (Bernard, 2002; Groves, 1990; Aday, 1996), absence of visual or nonverbal cues (Groves, 1990) and need for shorter interview time (Aday, 1996). These were seen to be similar challenges faced with the current study.

With hypertension as one of the most common yet modifiable risk factor for CVD (Chobanian, et al., 2003; Strandberg, Salomaa, Vanhanen, & Pitkala, 2001; Yusuf et al., 1998) attention needs to be paid to its development within the SCI population. Ezzati et al. (2008) reported that hypertension was a leading risk factor for cardiovascular and cerebrovascular disease and mortality in the general population. Similarly CVD has been reported to be a major cause of morbidity and mortality in patients with SCI and disorders (Banerjea et al., 2008; Bauman & Spungen, 2008; Garshick et al., 2005). It has been suggested that patients with SCI and disorders experience CVD at an earlier age compared with the general population (Yekutieli et al., 1989). Despite this, the risk for hypertension has been shown to increase with age in individuals with paraplegia and incomplete injuries (Grigorean et al., 2009; Furmaga et al., 2008). Adriaanse et al. (2016) further reported that high blood pressure was common in people with SCI and suggested screening for hypertension during annual check-ups, especially in those with a SCI below C8. While the baseline information highlighted a small portion of this population with hypertension,

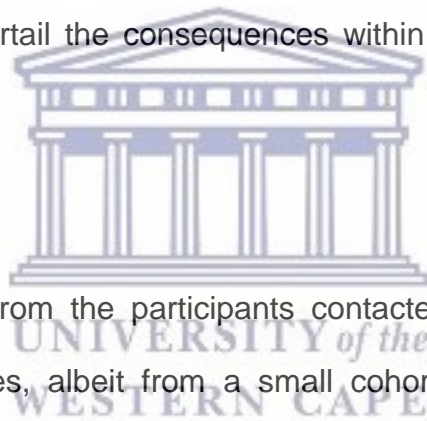
placing them at risk for CVD, the one-year follow-up data was postulated to showcase the development of the disease process over a period of time.

Despite the above-mentioned challenges in the collection of CVD risk data from the original incidence cohort, meaningful correlations was attempted to ascertain if there were any significant findings that could be gleamed from the data. Only one of the participants contacted from the original cohort reported being diagnosed with hypertension since being discharged from hospital. Inconclusive statistical significance was seen when looking at hypertension diagnosis before and after TSCI. The researcher attributed it to the low rate of hypertension seen in the small sample of interviewed participants. Despite the low number of participants contacted, other possible reasons for this could be related to the slow development of the disease process and the fact that insufficient time had elapsed to ascertain the development therefore. The fact that a moderately young cohort was interviewed, with a mean age of 39.16 years old, might be an additional factor as disease processes are normally only seen to occur in older population groups (Wolff et al., 2002; Guralnik, 1996). Contradictory to this premise are the findings of Yekutieli et al. (1989) who reported earlier onset of CVD in the SCI population. A limitation in the current study was that no follow-up physical measurements were taken to confirm a diagnosis of hypertension and this would be a suggestion for future research. Additional research is therefore considered necessary to ascertain the risk individuals with TSCI face in developing hypertension because of physical inactivity.

Limited research is available on individuals smoking at the time of their TSCI. Baseline information around smoking and alcohol consumption is important in understanding the propensity for risk behaviour activities that impact secondary health conditions and early mortality after TSCI. Only one study in the United States reported on pre-injury cigarette smoking among those with TSCI (Saunders et al., 2015). The study findings inferred that the predominance of smokers at the time of their SCI was 37.9%, considerably higher than the rate for those in the general population from the same geographic district (22.8%). Moreover, the individuals who were smokers at SCI onset, by and large, were older and had less formal education. Interesting to note was that this study's inclusion criteria for age were at least 16 years of age at assessment, which was younger than our study. The findings in this study were almost double that of other developed countries' results and suggested a greater level of engagement in smoking at the time of the injury. Further research is required to investigate this causative factors leading to this increased rate locally as smoking has been linked to the onset of CVD. A limitation in our study was that frequency of smoking was not recorded and should be considered in future studies.

The majority of participants who smoked at baseline, resumed once reintegrated back into their respective communities. A previous study reported cigarette smoking as a high-risk behaviour with an elevated prevalence at the time of SCI onset (Saunders et al., 2015). The few studies conducted on prevalence after injury have shown smoking rates between 22% and 48% (Saunders et al., 2014; Haisma et al., 2007; Linn, Adkins, Gong, & Waters, 2000) which was similar to the present study's finding. The lack of research in this area becomes concerning when looking at the adverse consequences of smoking after SCI and that it is a major cause of chronic

illness. Previous studies have reported that smoking is associated with poor endurance capacity and greater risk of obstructive lung dysfunction (Haisma et al., 2007; Linn et al., 2003). Pain severity is increased following exposure to nicotine in persons who have a history of smoking (Richardson et al., 2012; Richards et al., 2005). Furthermore, other health outcomes affected by smoking are an increased risk of hospitalisations, recurrent pressure ulcers, and mortality post injury (Krause et al., 2009; Krause & Saunders, 2009; Garshick et al., 2005; Krause & Broderick, 2004). In addition, smoking has been directly linked to increased risk of mortality among persons with SCI (Krause & Saunders, 2012; Garshick et al., 2005; Davies & McColl, 2002), highlighting the need to understand this phenomenon and identify prevention strategies to curtail the consequences within this vulnerable population group.



The subsequent findings from the participants contacted after being reintegrated back into their communities, albeit from a small cohort of participants, seem to suggest that pre-injury smoking is strongly linked to post-injury smoking rates. It further leads to questions around appropriate prevention strategies within the TSCI population group to curtail this high likelihood. In the general population counteractive action strategies focused on smoking-cessation programmes helped smokers quit. Educational programmes offered through the schools provided intercessions at an organisational level. At the community and societal level, increases in cigarette expenses and bans on smoking in eateries, work environments, and open communal spaces have aimed at decreasing smoking in the general public.

Although this study provides valuable information on smoking in a small population-based cohort of persons with TSCI, there were several limitations. First, the present study relied solely on self-reported data, without corroboration via medical records or other independent sources. Second, the response rate was poor; therefore, we are not able to ascertain smoking status on those who did not respond. Thus, findings may not therefore be generalisable to TSCI population. More research is necessary to see if these prevention strategies work within the SCI populations group.

For alcohol consumption, over half of the incidence cohort reported consuming alcohol prior to their TSCI. Again, this was seen mostly in males. This further elucidates males' propensity to engage in high-risk behaviours regardless of the often devastating consequences. When considering pre-injury use of alcohol prior to TSCI, research findings from more than 20 years ago have shown them to be raised in individuals who sustain SCI compared to the general population (Bombardier & Rimmele, 1998) and was significant in causing the SCI. The excessive consumption of alcohol at the time of the injury saw intoxication levels in 17-62% of SCI persons (Kolakowsky-Hayner et al., 2002; McKinley, Kolakowsky, et al., 1999; Young et al., 1995). The limitation in our study was that toxicology was not reported upon admission to hospital. It would have been interesting to obtain this information and see if in fact there was a correlation, but considering that many patients were admitted from secondary hospitals, this might have been difficult to execute consistently. Information on alcohol use was rather obtained from self-reported questionnaires. It was common in 50% of the population, which was consistent with previous reports of high alcohol problems pre-injury (Stroud et al., 2011; McKinley, Kolakowsky, et al., 1999; Bombardier & Rimmel, 1998; Young et al., 1995). This link

would be important to assess further so as to ascertain the need for prevention strategies in this high-risk population group. Such intercessions may have noteworthy ramifications for advancement amid recovery and change following hospital discharge.

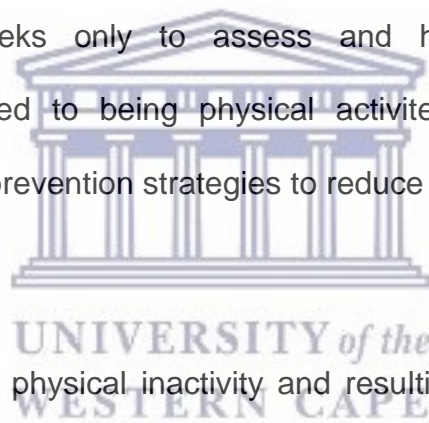
Alcohol consumption prior to SCI has been shown to have several implications post injury. Adverse medical and rehabilitation outcomes have been reported as a consequence affecting functional independence, decreased outcomes during hospital rehabilitation (Bombardier, Stroud, Esselman, & Rimmele, 2004) and decreased engagement in useful therapeutic activities during hospital rehabilitation (Heinemann, Goranson, Ginsberg, & Schnoll, 1989). Furthermore, history of pre-injury alcohol has been seen to affect the occurrence of medical complications post-injury (Elliott et al., 2002; Heinemann & Hawkins, 1995) and even was linked strongly with an increased likelihood of bankruptcy following injury (Hollingworth et al., 2007). These variables are important to consider when looking at this population group in the South African context where poverty rates are already high and those who were working at the time of the injury face the economic implications of their injury. South Africa has one of the highest alcohol consumptions in the world per head for all individuals who drink alcohol (Rehm et al., 2003). Intervention strategies might therefore be important both during and after the rehabilitation phase especially considering the high rates of alcohol consumption in the general population. Further studies have highlighted the critical “window of opportunity” to address alcohol problems in this population group during in-patient rehabilitation (Kolakowsky-Hayner et al., 2002; Bombardier & Rimmele, 1998).

Alcohol use during the first year following TSCI was seen in about a quarter of the contactable participants. Concerning was that one male participant reported consuming “too much” when he indulged in alcohol consumption. Post-injury alcohol use has appeared to be a main source of mortality among people with SCI (Krause et al., 2009; Go et al., 1995). Despite many persons with TSCI not consuming alcohol after their injury, rates among people with SCI seem, by all accounts, to be very high. One study reported that almost 50% of the people with SCI consumed alcohol prior to their injury reported consuming alcohol one year following their injury (Kolakowsky–Hayner et al., 2002). Even higher rates of return to alcohol consumption was reported with up to 75% of individuals with SCI who used alcohol prior to injury returning to drinking within 7–18 months post injury (Banerjea et al., 2009; Heinemann et al., 1991). A limitation in the study was that data was obtained from a small portion of the original incidence cohort who were contactable, limiting the generalizability of the results. Furthermore, under-reporting could also not be tested in the high-risk contactable cohort. More research is necessary to understand the implication of alcohol consumption following TSCI and links to the development of CVD.

Despite the low occurrence of chronic disease found in the study, several participants identified limited education around CVD received from healthcare practitioners as a point of concern. Interviewed participants eluded to the need for this type of education given their increased risk and desire curtail its possible future occurrence as seen from one of the participants comments, *“I think it is yes, it is... So I can try and avoid them so... I might think that I’m safe and then all of a sudden, I might get them (CVD).”* This indicates a willingness to understand CVD and make

the necessary adjustments to their health behaviour. This might be emphasised even more in this population group given their altered physical abilities following their TSCI. Only one participant reported being given sufficient information about CVD while in hospital citing, *“I know they spoke about all of this stuff (CVD). They sounded like a broken record.”* This could be due to individuals not being ready to hear this type of information given that they might only just be coming to terms with their disability and alternative focus on rehabilitation while in hospital. Meyers et al. (2007) suggest that comprehensive CVD risk-factor evaluation should be an integral part of every clinical visit for individuals with SCI. Education regarding CVD from healthcare professionals while in hospital or even after they had been discharged back into their respective communities seemed sparse and the majority of participants cited not receiving any information about CVD. The devastating consequences following a TSCI already disadvantage individual’s ability to function normally within society. Additional health conditions would therefore further disadvantage this vulnerable population group and add to the numerous challenges faced within their respective communities. A multi-facet approach needs to be explored to better support this disabled population in order to allow individuals with TSCI to make more informed health decisions to curtail the onset of secondary health conditions, specifically with regard to CVD. More research is necessary to understand whether sufficient patient education is done in the South African public healthcare context or if the load placed on the public healthcare system sees healthcare professionals focusing on other medical issues deemed by them to be more pertinent.

The study findings indicate that participants' physical activity levels are dependent upon a blend of physiological, socio-environmental components, changing from case to case, and making conventional CVD counteractive action programmes problematic. Relevant factors particularly seen through the focal points as barriers and facilitators to being physically active might be separated by these physiological, motivational or socio-environmental inceptions. All participants recognized various factors as having an effect on their physical activity levels. In arranging the common themes found in the interviews, recognition is given to the intertwined connection between the previously mentioned variables. An endeavor to disentangle or limit the potential links between these components would be to distort the experiences reported. This thesis seeks only to assess and highlight individual's lived experiences as it pertained to being physical active within communities and suggests the possibility of prevention strategies to reduce the occurrence of CVD.



Increased BMI because of physical inactivity and resulting hypertension has been well documented in literature for the SCI population. Interviews noted participants concerns around increased BMI with one participant reporting, *"Yes, I picked up... I'm fat now"*. A shortcoming in the study was that physical parameters for changes in weight were not recorded to support participants' statements. Possible under- or over-reporting of weight could not therefore be assessed and thus affects the trustworthiness of the data provided. While BMI has been proven useful in identifying individuals at risk for CVD in the general population (Jakicic et al., 1993), concern has been expressed that body composition changes secondary to long-term paralysis make interpretation difficult (Nuhlicek, 1988). What is evident is that more conclusive research is required to ascertain linkage between increased BMI, physical

inactivity and CVD in the SCI population.

Participants reported several impairments with regard to body function, which subsequently affected their ability to be physically active within their homes and communities. These impairments varied from case to case with some participants placing emphasis on pain while others placed emphasis on weakness and movement-related function. One of the participants who highlighted pain as a limiting factor stated, *“So ok when the pains comes it’s like affecting my whole spine making me, I can’t move, it’s like my legs is heavy. It’s like my left arm is heavy.”* Previous studies have reported muscle weakness and decreased lean mass following SCI. In the week’s post-SCI, there is a reduction of up to 40% of skeletal muscle size in the lower extremity (Spungen et al., 2003; Castro, Apple, Hillegass, & Dudley, 1999). Several participants reported weakness in different body parts and given the loss in muscle strength seen with the normal aging process, increased challenges in their ability to be physically active is expected to occur as this population ages. Specifically one participant reported, *“I’m walking but not like before cause the strength isn’t always there.”* Furthermore, serious metabolic consequences are seen following the rapid loss in muscle mass (Monroe et al., 1998; Bauman & Spungen, 1994; Mollinger et al., 1985), with the resulting energy imbalance causing individuals’ BMI to increase. This was reported to be the case in several of the study participants interviewed and is similar to the findings of two other studies (Gorgey & Gater, 2011; Spungen et al., 2003). Time will only tell if this is cause for concern in the SCI population within South Africa. The researcher postulates that there is the potential for an even greater increase in BMI given the multi-dimensional barriers faced by

individuals with TSCI endemic to the South African context but this needs further investigations.

In addition, pain has been reported to be prevalent in individuals with SCI by numerous studies to varying degree. Finnerup (2013) claimed that chronic pain was common in SCI patients in up to 70%, in his study to present an update on the classification of SCI pain. Previous studies have put the average at 65% of people with SCI experiencing pain and in nearly 30% the pain is rated as severe (Siddall et al., 1999; Demirel, Yilmaz, Gencosmanoglu, & Kesiktas, 1998; New, 1997; StoÈrmer et al., 1997; Levi, Hultling, Nash, & Seiger, 1995). The methodology and the patient population being studied however appear to greatly influence the reported incidence of pain in the SCI population. Additional secondary health complications due to the sedentary nature of SCI, include CVD (DeVivo et al., 1999), hypertension (Figoni, 2009; Jacobs & Nash, 2004), orthostatic hypotension (Figoni, 2009; Teasell, Arnold, Krassioukov, & Delaney, 2000), glucose intolerance and/or insulin insensitivity (Jacobs & Nash, 2004; Buchholz, McGillivray, & Pencharz, 2003), as well as urinary tract infections (McKinley, Jackson, Cardenas, & DeVivo, 1999; Cardenas & Hooton, 1995), pressure sores (Figoni, 2009; McKinley, Jackson, et al., 1999) and osteoporosis (Figoni, 2009). These secondary health conditions may lead to re-hospitalisations and on-going health interventions may be necessary to manage these conditions (Guilcher et al., 2010; Jaglal et al., 2009; Dryden et al. 2004; Cardenas, Hoffman, Kirshblum, & McKinley, 2004; McKinley, Jackson, et al., 1999).

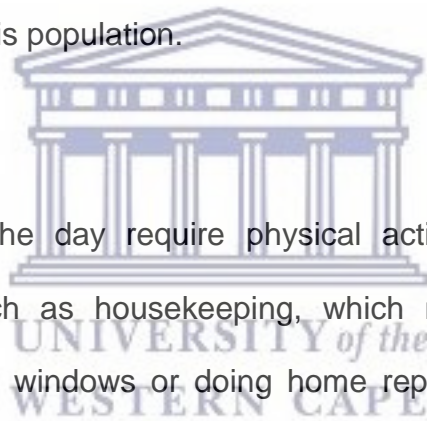
The benefits of physical activity have been reported earlier in this dissertation. Specific references however is now made to the benefits seen in enhanced

cardiovascular, and muscle function (Wolfe et al., 2012), reduction in pain and depression (Latimer et al., 2004; Martin Ginis et al., 2003), increased mobility (Manns & Chad, 1999; Noreau & Shephard, 1995), and perhaps, most importantly, enhanced physical independence (Manns & Chad, 1999) and physical capacity (Jacobs & Nash, 2004).

Participants reported being aware of the benefits of being physically active, *“So I know the benefits and then the gap in my life was when the accident happened, and the rehab. In those few months, I saw what can happen if you’re not physically fit. And then also, with the limited function I have left, I saw that I need to strengthen myself and use the muscles I can still use. So that is why, being physically fit and being able to participate in a training program or any activity, it is actually vitally important for me now.”* This highlights how knowledge around the benefits of physical activity can improve the physical activity level of individuals. This self-directed motivation was gleaned through experience and speaks to the self-efficacy theory believed to be useful in rehabilitation (Picha & Howell, 2018). This would be a useful strategy in planning CVD prevention programmes, as patients spend limited time engaging with a healthcare professional once they have been discharged from hospital and need to continue their home exercise. Motivation of these individuals is key.

The majority of the participants reported being engaged in some sort of physical activity or recreational activity prior to their TSCI. Few were seen to be engaging in physical activity following their TSCI and subsequent community reintegration. The

type and amount or intensity of the physical activity engaged was not assessed and is seen as a possible limitation. Physical activity participation is important for all individuals, but especially for persons with SCI as the majority of this population engage in little to no physical activity (Bowen et al., 2009; Rimmer & Schiller, 2006; Rimmer, Riley, Wang, & Rauworth, 2005; Scelza et al., 2005; Zemper et al., 2003) and have been broadly classified as extremely sedentary (Jacobs & Nash, 2004). There have been several authors who have highlighted the important role of physical activity for person with SCI (Fernhall et al., 2008; Nash, 2005; Jacobs, Nash & Rusinowski, 2001; Washburn & Fignoni 1999; Cowell, Squires & Raven, 1986) but little is known about the optimal exercise modality for the various subcategories of individuals that comprise this population.



Various activities during the day require physical activity and increase energy expenditure. Activities such as housekeeping, which may include sweeping or vacuuming floors, cleaning windows or doing home repairs all required increased energy expenditure. Some of the participant encountered several challenges with ADLs once at home given their limited functional abilities following TSCI. One participant in particular cited the impact on their function after coming home: *“Just the mere fact you can’t actually just come back and do everything that you were able to do before the injury.”* It becomes prudent to be aware of the barriers that interfere with physical activity for persons with SCI. Sometimes they are as simple as doing activities within the home to more complex activities outside of the home. The barriers reported by the participants in the study varied from factors within their homes, their external environment, and transportation, to confidence issues as they reintegrated back into their respective communities. Some of the barriers identified

for physical activity in literature include the availability, cost and accessibility of both transportation (McVeigh, Hitzig, & Craven, 2009; Vissers et al., 2008; Carpenter et al., 2007; Scelza et al., 2005; Rimmer et al., 2004) and fitness facilities/services (Vissers et al., 2008; Carpenter et al., 2007; Rimmer et al., 2004). These barriers were seen to be similar challenges reported by participants in the current study.

Transportation was highlighted as a considerable barrier when participants wanted to engage in physical activity within their respective communities in the Cape Metropolitan area. Research has identified transportation as an important resource for the general population, but even more so for the disabled population, as it connects people to the broader society and allows them to engage in numerous activities one which is physical activity. Lin et al., (2009) investigated subjects with SCI and noted transportation as one of the more prominent barriers to community participation, specifically highlighting return to productive activity. This was confirmed by the comments of participants in the study, with one participant saying, *“Transportation is the biggest barrier we face as disabled people”*. Several other studies have identified transportation as a barrier, which often prevents this population from accessing needed medical and rehabilitative resources (Boschen, Tonack, & Gargaro, 2003; O’Day, Dautel, & Scheer, 2002). According to Silver, Ljungberg, Libin, and Groah (2012), transportation often limit the geographical area where individuals can receive medical services and/or lead to missed appointments. This, the researcher believes, can be seen to further disadvantage an already disadvantaged population group. A participant in the study reported that accessibility was the main challenge citing, *“The transportation is not accessible to you, which really frustrates some of the disabled people”*. This emerged as one of the major

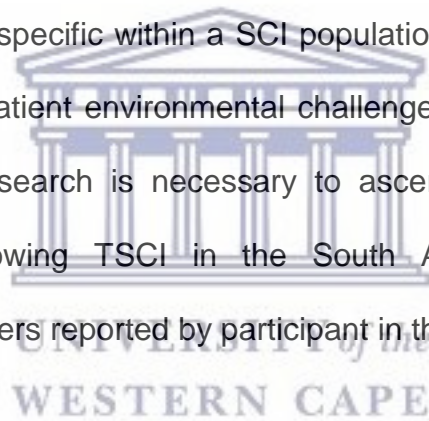
barriers experienced by the interviewed cohort, as transportation was the medium used to access their communities and their ability to be physically active often hinged on their ability to get to a set destination. More local research is necessary to determine more comprehensively the barriers experienced by individuals with SCI and a multi-sectorial and multi-disciplinary team approach is then suggested to address the challenges experienced creating a more inclusive society.

While some participants reported making some changes to their homes, which is seen to be a facilitator for physical activity, space was a noteworthy barrier for many of the participants living on the Cape Flats and affected their ability to be physically active. This led to increased time spent on individual home-based activities. Two different participants reported being very sedentary following being at home after their TSCI. One reported *"I'm just watching TV all day there. Is nothing else I am doing"*. Another one said, *"I'm sitting around in my wheelchair every day"*. This highlights a common factor for TSCI patients who need to learn a new way of functioning within their home given their altered functional abilities. This was similar to the findings of Barclay et al. (2011), who reported an increase in home-based activities such as watching television, listening to the radio, and reading. Concerning was that this behaviour was reported to potentially lead to social isolation (Brown, et al., 2002). This was something that also seemed to emerge in the study limiting the inclusion of these individuals within the broader context of society and needs targeted study and intervention to facilitate an improved reintegration back into their social circles allowing for increased physical activity. More research is required to guide community resource allocation and support for individuals with TSCI to support their transition home and curtail them being sedentary when they come home.

In general, there is limited evidence on the high susceptibility to medical complications and secondary chronic conditions within the SCI population due to sedentary lifestyles. Conditions commonly seen within this population group are urinary tract infections, diabetes, pressure ulcers, obesity, osteoporosis, arthritis and CVD (Groah et al., 2002; Bauman, & Spungen, 2000, 1994; DeVivo et al., 1999; Karlsson, 1999; Duckworth et al., 1980). Physical activity has been shown to help prevent such conditions (Jacobs et al., 2001) and improve individuals' social integration and quality of life (Manns & Chad, 1999; Noreau & Shephard, 1995, 1992) and improves physical functional abilities (Duran, Lugo, Ramirez, & Eusse, 2001; Manns & Chad, 1999; Noreau et al., 1993). Consequently, the engagement in physical activity is recommended as a key component of health interventions for people with SCI (Martin Ginis, Latimer, et al., 2010; Latimer, Martin Ginis, Craven, & Hicks, 2006; Hicks et al., 2003). Despite these assertions and the relative plethora of evidence related to the benefits of physical activity, individuals' ability to have a physically active lifestyle have several challenges. Previous studies have identified accessibility, pain, costs, psychological barriers, a lack of motivation and energy, and a lack of logistical information as considerable challenges (Vissers et al., 2008; Scelza et al., 2005; Zemper et al., 2003). This was consistent with many of the participants' comments that cited similar barriers.

Leisure-time physical activity (LTPA) activities such as sports participation, exercise conditioning or training and recreational activities, such as going for a walk, dancing and gardening (O'Sullivan & Schmitz, 2007). In one population-based study on LPTA, only 50% of people with SCI reported to be engaged in LTPA (Martin Ginis, Latimer, et al., 2010). This was similar to the current study's findings and leads to

further questions around the possible difficulties experienced by the SCI population group to engage in LTPA. Some of these barriers reported have been mentioned earlier in this discourse. A few participants reported being engaged in numerous sporting codes. One reported, *“My main sport that I actually play is wheelchair basketball.”* While another reported *“ I’m involved with wheelchair rugby, and I joined the gym”*. Involvement in sporting codes is therefore seen to be a facilitator for physical activity and the researcher proposes that this will assist in curtailing the onset of CVD. This is supported by the findings Hicks et al. (2011), who conducted a systematic review of the benefits of LTPA and concluded that it was associated with better health and fitness among individuals with SCI. The complexity of being physically active is patient-specific within a SCI population group and requires more comprehensive study as patient environmental challenges within any given context vary. More longitudinal research is necessary to ascertain how physical activity levels are impacted following TSCI in the South African context especially considering the varied barriers reported by participant in the study.



The present study findings compared with literature have illustrated a growing concern among the TSCI population that highlights the increased risk for CVD due to decreased physical activity specifically within a regional population in South Africa. The barriers impacting physical activity are numerous and varied. Better education during the rehabilitation phase might be a key component to individuals with TSCI making more informed decisions about prioritising physical activity as they attempt to reintegrate back into their respective communities. The removal of some of the socio-environmental barriers highlighted above could allow motivated TSCI individual access to choosing how to increase physical activity levels. More longitudinal

research is necessary to understand how CVD risk change over time in the TSCI population specifically as it relates to physical activity levels. This will shed light on the factors affecting its development in this population and elucidate the need to prevention strategies in this already marginalised population.

7.4 CARDIOVASCULAR DISEASE PREVENTION PROGRAMMES FOR INDIVIDUALS WITH A TRAUMATIC SPINAL CORD INJURY

Exercise or physical activity has an impact on numerous systems in the body and the benefits extend across other areas of health, including mood, pain, and perceived health status (Crane et al., 2017). It has also been reported that exercise has been seen to be an important therapy strategy for reducing the risk for CVD and multiple co-morbidities (such as type 2 diabetes, hypertension, obesity) in the SCI population (Warburton et al., 2006). Structured small group exercise classes (Crane et al., 2017), circuit resistance training, a calorie-restrictive Mediterranean-style diet, and behavioural support (Bigford et al., 2017) were put forward as viable options for individuals with SCI. It highlighted numerous benefits with some being that it promoted exercise participation and increasing exercise intensity. Considering utilising small group exercise classes and circuit resistance training in the local context is however fraught with certain limitations. As reported in earlier chapters, challenges faced by many of the participants in the study were related to transportation, *“Transportation is the biggest barrier we face as disabled people”*. Getting to a designated location to participate in group exercises and circuit training might therefore be a challenge. Possible solutions for this could be the implementaion of more community-based interventions closer to the homes of individuals with TSCI. The adoption of a Mediterranean-style diet again might be problematic given the high poverty rate of

the study cohort and might require further investigation into alternatives that are more cost effective for our local context and population. Behavioural support could, however, be one of the strategies that could be adopted locally and should be considered by healthcare professionals who support the TSCI community during their rehabilitation as proposed by Myers et al. (2012). This could be done through DVDs/videos or brochures as highlighted by Thomas et al. (2011), and could be a viable option given the available resources of TSCI population locally. Important to note, however, is that certain barriers in a developing context like South Africa might need to be considered and adjustments might need to be suggested to meet the need and resources availability of the local SCI population. The involvement of a multidisciplinary team to assist individuals with SCI to reduce their CVD risk was seen to yield modest but significant changes (Myers et al., 2012). This might be problematic in a context like South Africa where limited healthcare professionals are already seen to be burdened with the management of acute and sub-acute patients and adding to what they need to do might be challenging. The limited information received from healthcare professionals in the study supported this notion with participants' comments like *"No advise. Nothing"* and *"... lack of information"*. While some participants reported that they did receive information citing *"they sounded like a stuck record"*, it raises questions around the consistency thereof. More research is suggested to target the perceptions of the healthcare professionals to provide this information to TSCI community. Contrary to the above mentioned benefits of exercise, Totony de Zepetnek et al. (2015) determined that the effects of implementing the physical activity guidelines (PAG) on CVD risk factors yield minimal improvement on many markers of CVD risk. More research is required to

ascertain the optimal prevention strategy for the SCI population to reduce and manage CVD risk.

Self-management interventions to promote an active lifestyle were seen to have mixed results. Kooijmans et al. (2017) cited that their 6-week self-management intervention was not effective to change behaviour toward a more active lifestyle and to improve perceived behavioural control, stages of change, and attitude in individuals with a long-term SCI. Contrary to this Libin et al. (2011) found YouTube to be a useful tool in educating people with SCI on making wiser health choices. Given the barrier to access, Youtube is seen as a potential option as it can be accessed anywhere as long as the individuals have access to the internet. This medium of educating the SCI population might prove beneficial in the South African context when appropriate content is developed to educate individuals with TSCI around the benefits of physical activity, possible suggestions of what they can do in their home context and also elucidate prevention strategies for the development of CVD. This, however, might be problematic in that internet access locally is costly and the TSCI cohort might not have the means to afford to access these videos. A better alternative would be the development of DVDs/videos and brochures as suggested earlier as this has fewer barriers to access and could even be held in a library setting where individuals could take out the resources on temporary basis if financial resources limit the production therefore in volume.

Given the study's observation regarding decreased physical activity levels and the subsequent decline seen in the local TSCI population, the researcher proposes that more targeted research is necessary within the local TSCI population. This would

assist in identifying the optimal CVD prevention strategies as the current study's scoping review revealed limited CVD prevention programmes or strategies for the SCI population group. These programmes might further need to be tailored to the available resources of individuals within a given context. This is especially necessary as the resources of the individuals with TSCI in South Africa are varied and often limited.

7.5 SUMMARY OF THE CHAPTER

This chapter reviewed the quantitative and qualitative findings from the study and positioned the results in relation to relevant literature pertaining to the incidence of TSCI, CVD profile and the facilitators and barriers associated with physical activity for this segment of the population in South Africa. The results indicated that individuals with TSCI were engaged in less physical activity following their TSCI and subsequent community reintegration due to a host of reasons. It was further demonstrated that a need exists for the implementation of CVD prevention programmes for this population given their increased CVD risk of the population owing to them living a more sedentary lifestyles. CVD prevention strategies were limited and further research is necessary to shed more light on appropriate CVD prevention programmes for the TSCI population.

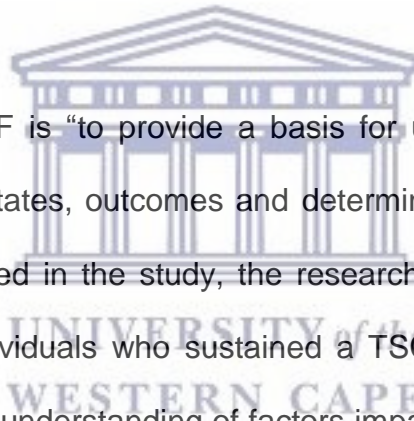
CHAPTER 8

CONCLUSION, RECOMMENDATIONS AND LIMITATIONS

8.1 INTRODUCTION TO THE CHAPTER

In this chapter the overall conclusions are provided followed by the study's recommendations. The chapter is drawn to a close with a delineation of the study's subsequent limitations.

8.2 CONCLUSIONS



One of the aims of the ICF is “to provide a basis for understanding and studying health and health-related states, outcomes and determinants” (WHO, 2001). As the theoretical framework utilised in the study, the researcher attempted to establish a demographic profile of individuals who sustained a TSCI, during the study period, providing a description and understanding of factors impacting physical activity levels of a specific group of individuals living with a TSCI in a regional area of the Western Cape province. The main aim of the study was to assess and explore the need for the implementation of CVD prevention programmes after sustaining a TSCI in a regional South African population.

The study was carried out on the basis that there is limited national data available that looks at people with a TSCI and their risk for developing CVD specifically as it pertained to their physical activity levels once reintegrated back into the community.

In addition, international research indicates that the SCI population is at significant risk for secondary complications. This has been purported to be due to their subsequent functional disability after a SCI and has further been suggested to be because of poor lifestyle habits and physical inactivity.

Results from the qualitative phase of study were obtained from a small sample size and could have influenced the findings and conclusions drawn. Caution should be taken when looking at these results and general assumptions should not be made for either the study population or the TSCI populations at large. Despite this, the results could still be deemed relevant, as the researcher could not find other studies with persons with TSCI, both nationally or internationally, with similar objectives.



The demographic findings of this study indicate that individuals sustaining a TSCI in the Cape Metropolitan area of the Western Cape province in South Africa, are more than likely to be young and male, either from the Coloured or Black African race grouping and living in the Cape Flats. The etiological findings highlighted the main causation of TSCI to be most likely as result of assault. Neurological classification of TSCI demonstrated ASIA classification A and D to be the most common classification in more than three quarters of the cases. The distribution of paraplegia and tetraplegia classifications was fairly evenly distributed.

The CVD risk of persons who sustained a TSCI in the Cape Metropolitan area, at baseline, was high with a large portion of the sample being engaged in high risk

behaviour i.e. smoking and alcohol consumption. The fairly young cohort might have impacted the presence of hypertension at baseline with very few being diagnosed with hypertension prior to their TSCI. Furthermore, the average blood pressure readings recorded of individuals with TSCI, while in hospital, was seen to be within the normal range according to parameters stipulated by The American Heart Association (2016).

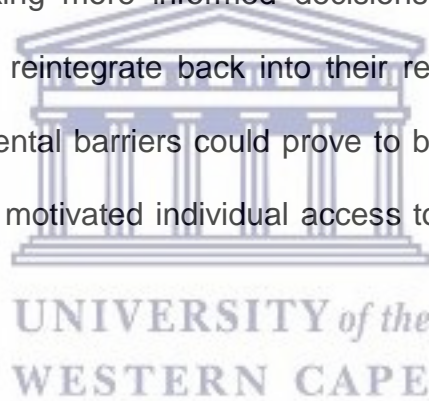
Longitudinal follow-up data was difficult to obtain for numerous reasons. The contactable cohort reported low rates of hypertension diagnoses but this should be viewed with caution due to the small sample size. Many of the participants were seen to return to previous high-risk activities following TSCI with smoking and alcohol consumption being significant. Several participants were involved in some sort of physical activity once reintegrated back into their respective communities but this was not able to be confirmed and is open to desirability bias.



Semi-structured interviews and the focus group discussion conducted during the qualitative phase of the study looked at the impact of TSCI on physical activity once individuals were reintegrated back into their community. It highlighted considerable challenges experienced by participants. Participants reported several impairments with regards to body function, which subsequently affected their ability to be physically active within their homes and communities. These impairments varied from case to case with some participants placing emphasis on pain while others placed emphasis on weakness and movement-related function. Despite understanding the associated benefits of being physically active, barriers to physical

activity reported by the participants varied from factors within their homes, access to their external environment, and transportation as they attempted to engage in physical activity. These were similar to the findings in literature and highlighted the challenges experienced by the disabled population in general.

The present study's findings, compared with literature, have illustrated a growing concern among the TSCI population for increased risk for developing CVD due to decreased physical activity. The barriers impacting physical activity are numerous. Better education during the rehabilitation phase might be a key component to individuals with TSCI making more informed decisions about prioritizing physical activity as they attempt to reintegrate back into their respective communities. The removal of socio-environmental barriers could prove to be one of the most effective facilitators, thus allowing a motivated individual access to choosing how to increase physical activity.



Prevention strategies were limited but highlight that the engagement in physical activity is vital in curtailing the development of CVD. Self-management strategies might be a viable option given the limited access and resources of individuals with TSCI locally but some of strategies identified were dependent on access to the Internet.

8.3 RECOMMENDATIONS

Based on the study findings, a number of recommendations are made:

1. Individuals with TSCI come into contact with numerous healthcare professionals during the acute and subacute management of their injury. It is therefore recommended that while in hospital, healthcare professionals should screen these individuals for CVD risk. This is done to identify the risk profiles of individuals and suggest appropriate intervention strategies to reduce individual's future risk. This can be commenced during the in-patient rehabilitation phase, which is seen as a "window period" where individuals are open to health promotion activities as they come to terms with their disability and start to get their life back on track following the SCI.


2. Individuals accessing community based healthcare services should also be screened regularly by healthcare practitioners to identify changes to individuals health risk profile so that appropriate interventions could be started earlier. This could drastically impact the progression of CDL experienced by these individuals, specifically CVD.



3. Furthermore healthcare professionals should augment their services to include individualized CVD health promotion and prevention strategies for SCI individuals who have a higher propensity towards physical inactivity. These health promotion strategies should be tailored to the individual's needs and functional abilities.

4. Once individuals with TSCI are discharged back into their respective communities, training and support workshops should be organized or these individuals should be referred to existing groups, to assist in the formation of community based support structures for continued health promotion practices.

5. Social support received from family and friends following a TSCI was highlighted as an important variable for making positive health-related behaviours choices. As a result of the importance of emotional support given to individuals with TSCI following reintegration back into their community, it is recommended that care givers of individuals with TSCI be involved in the CVD education and home based exercise prescription training while in hospital. This the researcher believes could support individuals with TSCI to improve physical activity levels because someone else knows what they need to do and could further assist in keeping individuals accountable for healthy life choices as it pertained to smoking, alcohol consumption and exercise.



6. Additional research is necessary regarding TSCI prevalence and incidence in South Africa. The results of more comprehensive research could inform national government more emphatically around possible prevention strategies employable to curtail the occurrence of these life-changing events. It could further assist identifying activities and foci for multi-disciplinary teams and multi-sectorial stakeholders to improve the reintegration of these disabled individuals back into society.

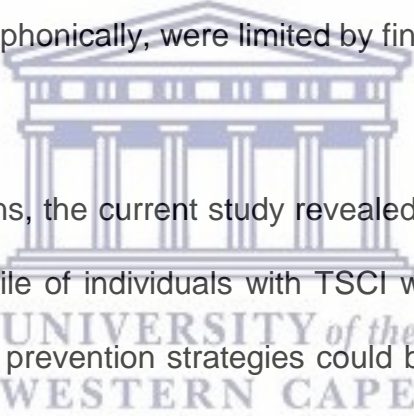
7. Lastly, the findings of the study could serve as a starting point for larger research studies covering the rest of South Africa, to understand how the CVD risk profile changes over time for individuals with TSCI within a specific population. The execution of similar studies in other African countries could be undertaken to understand the phenomenon experienced on the continent, which is largely comprised of developing countries.

8.4 LIMITATIONS OF THE STUDY

The findings of the present study should be interpreted in the light of the following limitations:

- Certain quantitative and qualitative data were based on self-reporting. This can be seen to lend itself to desirability bias where participants are seen to over-estimate or under-estimate specific tested variables. Several researchers have however provided sufficient evidence supporting the use of self-reporting highlighting its reliability and validity (Craig et al., 2003; Woodward et al., 2000).
- Purposive sampling was used as the methodological approach to select participants for the semi-structured interviews and focus group discussion. Qualitative studies utilise smaller sample groups compared to quantitative studies, in order to obtain in-depth information. This was the case in the current study and therefore generalisation of the study findings for the TSCI is limited given the small sample size.
- Only individuals who were on government funded healthcare insurance were included in this study thereby excluding private healthcare individuals who sustained a TSCI. Due to the procedural and structural differences between the two systems in South Africa, transferability might be difficult and challenging but there might be similarities.
- Although the CVD baseline data of the study were collected from GSH ASCI unit only, other primary and secondary hospitals may have admitted individuals with acute TSCI and these may not have required further management at GSH ASCI unit thereby affecting the applicability of CVD baseline data to the broader TSCI population locally.

- The sample for the focus group discussion and semi-structure interviews used in the study was relatively similar and therefore generalisation of the study findings for the TSCI is limited.
- There was limited representation of ethnic minority groups as well as females.
- After data was collected it was then captured by the researcher, coded and then analysed by the same researcher. It is proposed that greater rigor would have been achieved if the captured data was coded and analysed by additional researchers.
- In addition, the sample size for one-year follow-up phase of the study was relatively small and challenges contacting participants through different mediums, barring telephonically, were limited by financial and time constraints.



Despite the study's limitations, the current study revealed several interesting insights regarding the CVD risk profile of individuals with TSCI within the Western Cape, of South Africa. The proposed prevention strategies could be useful as a starting point for further research, for individuals living with TSCI to be more physically active and assist them in curtailing the onset of many of CVD within the South African context.

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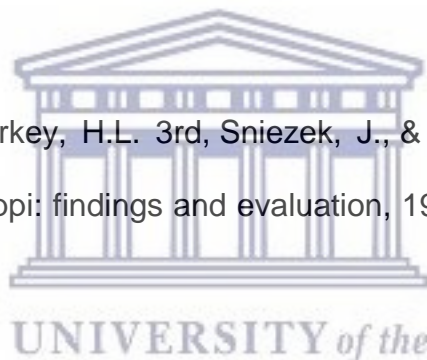
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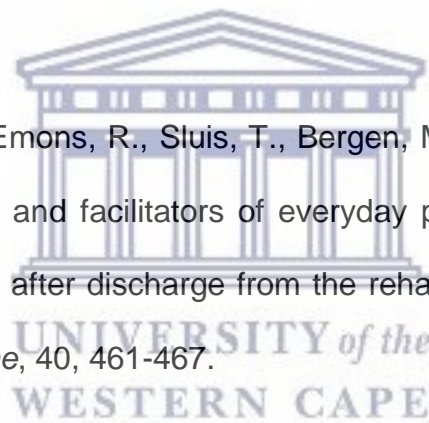
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Appendix 1 Ethics Letter from University of the Western Cape



OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT

20 May 2013

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape has approved the methodology and ethics of the following research project by:
Prof J Phillips (Physiotherapy)

Research Project: Risks for chronic diseases of lifestyle after spinal cord injury - a new challenge.

Registration no: 13/4/27

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

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

Private Bag X17, Bellville 7535, South Africa
T: +27 21 959 2988/2948... F: +27 21 959 3170
E: pjosias@uwc.ac.za www.uwc.ac.za

A place of quality,
a place to grow, from hope
to action through knowledge

Appendix 2 Ethics letter from Groote Schuur Hospital



GROOTE SCHUUR HOSPITAL

Enquiries: Dr Bhavna Patel

E-mail : Bhavna.Patel@westerncape.gov.za

Professor Julie Phillips
Physiotherapy Department
University of the Western Cape
Private Bag X17
BELLVILLE
7353

E-mail: jphillips@uwc.ac.za

Dear Professor Phillips

RESEARCH PROJECT: Risks for Chronic Diseases of Lifestyle after Spinal Cord Injury – a New Challenge

Your recent letter to the hospital refers.

You are hereby granted permission to proceed with your research.

Please note the following:

- Your research may not interfere with normal patient care
- Hospital staff may not be asked to assist with the research.
- No hospital consumables and stationary may be used.
- No patient folders may be removed from the premises or be inaccessible.**
- Please introduce yourself to the person in charge of an area before commencing.
- Confidentiality must be maintained at all times.

I would like to wish you every success with the project.

Yours sincerely

A handwritten signature in cursive script that reads 'B Patel'.

DR BHAVNA PATEL
SENIOR MANAGER: MEDICAL SERVICES

Date: 27th July 2013

C.C. Ms C. Davids
Mr L. Naidoo

G46 Management Suite, Old Main Building,
Observatory 7925

Tel: +27 21 404 6288 fax: +27 21 404 6125

Private Bag X,
Observatory, 7935

www.capegateway.gov.za

Appendix 3 English consent form



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-9592542, Fax: 27 21-9591217
E-mail: marc.anton.naidoo@gmail.com

CONSENT FORM

Title of Research Project: The risk of chronic diseases of lifestyle after traumatic spinal cord injuries in the Cape Metropolitan.

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Participant's name..... Witness.....

Participant's signature.....

Date.....

UNIVERSITY of the
WESTERN CAPE

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator's Name: Naidoo, Marc

University of the Western Cape

Private Bag X17, Belville 7535

Telephone: (021)959-2542

Cell: +27833889960

Fax: (021)959-1217

Email: marc.anton.naidoo@gmail.com

Appendix 4 Afrikaans consent letter



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-9592542, Fax: 27 21-9591217
E-mail: marc.anton.naidoo@gmail.com

TOESTEMMINGSVORM

Titel van Navorsingsprojek: "The risk of chronic diseases of lifestyle after traumatic spinal cord injuries in the Cape Metropolitan"

Die studie was aan my beskryf in 'n taal wat ek verstaan en ek gee hiermee vrywilliglik toestemming tot deelname aan die studie. My vrae in verband met die studie was beantwoord tot my bevrediging. Ek verstaan dat my identiteit nie bekend gemaak sal word nie en dat ek kan onttrek aan die studie op enige tydstip sonder om enige rede te verskaf en dat my onttrekking geen negatiewe impak op my sal het nie.

Naam van deelnemer: _____

Getuie: _____

Handtekening van deelnemer: _____

Datum: _____



Indien u enige vrae aangaande hierdie studie het of enige probleme wat u ervaar het wil aanmeld kan u die studie koördineerder kontak:

Studie Koördineerder: Marc Naidoo

Universiteit van Wes-Kaapland

Privaat sak X17, Belville 7535

Telefoon: (021)959-2542

Fax: (021)959-1217

Email: marc.anton.naidoo@gmail.com

Appendix 5 isiXhosa consent form



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-9592542, Fax: 27 21-9591217
E-mail: marc.anton.naidoo@gmail.com

Iphepha Mvume Lomthathi nxaxheba

Title of Research Project: "The risk of chronic diseases of lifestyle after traumatic spinal cord injuries in the Cape Metropolitan"

Ndixelelwe malunga menjongo kwanendlela yoluphando. Ndiyaqonda ukuba yonke into endizakuyithethe izankungciwa iymfihlo. Xa ndifuna ukurhoxa koluphando ndinakao. Ndinako ukurhixa koluphando naliphi na ixesha ndingakhange ndanika sizathu. Ndinalo ilungelo lokurhoxa ekuphenduleni imibuzo nakulo oluphando kwaye oko akungeze kundichaphazele ngendlela embi.

Igama lomthathi nxaxheba:

Tyikitya:..... **Usuku:**

Ukuba unombuzo nxibilelana:

Marc Naidoo

University of the Western Cape

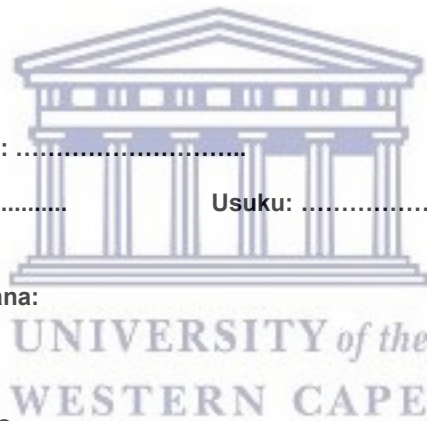
Private Bag X17, Belville 7535

Telephone: (021)959-2542

Cell: +27829921549

Fax: (021)959-1217

Email: marc.anton.naidoo@gmail.com



Appendix 6 English participant information sheet



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-9592542, Fax: 27 21-9591217
E-mail: marc.anton.naidoo@gmail.com

PARTICIPANT INFORMATION SHEET

Project Title: “The risk of chronic diseases of lifestyle after traumatic spinal cord injuries in the Cape Metropolitan”

What is this study about?

This is a research project being conducted by Marc Naidoo at the University of the Western Cape. The main aim of this project is to assess and explore the need for CVD intervention after sustaining a traumatic spinal cord injury in a regional South African population. I would also like to find out how you experience or perceive your reintegration into the community from a physical activity perspective.

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

We will ask you to answer questions related to your spinal cord injury; your chronic disease of lifestyle profile; to determine your risk behaviours linked to CVD risks; to determine your history of raised blood pressure and diabetes mellitus; to explore your experiences regarding physical activity participation and how it has affect you following your TSCI; and to explore your extent of social and community reintegration and the factors influencing you one year post injury.

Would my participation in this study be kept confidential?

We will do our best to keep your personal information confidential. To help protect your confidentiality your name and other vital information provided will be coded. Details of any information provided will be kept strictly confidential. Data collected will be kept in a pass worded computer and other saving devices.

If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

What are the risks of this research?

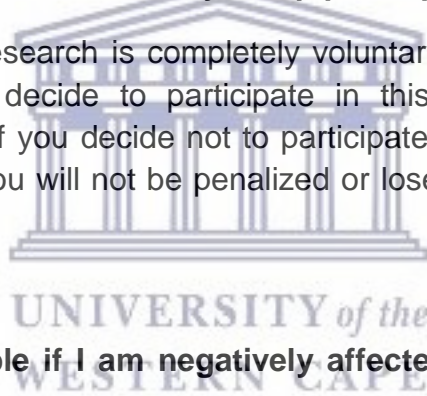
There are no known risks associated with participating in this research project. However, counselling services will be available to you if you should require them as a result participating in the research project.

What are the benefits of this research?

This research project will provide essential knowledge on to the risk profile of clients with traumatic spinal cord injuries for chronic diseases of lifestyle (CDL) and highlight the importance of awareness to screening for CDL post injury. This will illuminate the need for a coordinated healthcare system and improved communication between different governmental sectors as well as reorganise the resources allocation for this marginalised population.

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.



Is any assistance available if I am negatively affected by participating in this study?

You will be referred to appropriate health care professionals should there be a need for referral during course of the study.

What if I have questions?

This research is being conducted by Marc Naidoo of the Physiotherapy Department, University of the Western Cape. If you have any questions about the research study itself, please contact me at: Department of Physiotherapy, University of the Western Cape, Private Bag X17, Bellville 7535, South Africa or 0729082908, email: marc.anton.naidoo@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:

Head of Department: Prof Anthea Rhoda

University of the Western Cape

Private Bag X17

Bellville 7535

Dean of the Faculty of Community and Health Sciences: Prof J. Frantz

University of the Western Cape

Private Bag X17

Bellville 7535



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

Appendix 7 Afrikaans participant information sheet



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-9592542, Fax: 27 21-9591217
E-mail: marc.anton.naidoo@gmail.com

DEELNEMENDE INLIGTINGSBLAD

Projek Titel: "Die risiko van chroniese siektes van lewenstyl na traumatale rugmurgbeserings in die Kaapse metropolitaanse"

Waaroor gaan hierdie studie?

Hierdie is 'n navorsingsprojek wat deur Marc Naidoo aan die Universiteit van Wes-Kaapland gedoen word. Die hoofdoel van hierdie projek is om die behoefte aan CVD-intervensie te evalueer en ondersoek na die handhawing van 'n traumatiese rugmurgbesering in 'n plaaslike Suid-Afrikaanse bevolking. Ek wil ook graag uitvind hoe u u herintegrasië in die gemeenskap vanuit 'n fisieke aktiwiteitsperspektief ervaar of waarneem.

Wat sal ek gevra word om te doen as ek meedoen om deel te neem?

Ons sal jou vra om vrae wat verband hou met jou rugmurgbesering te beantwoord; jou chroniese siekte van lewenstylprofiel; om u risiko-gedrag te bepaal wat verband hou met CVD risiko's; Om jou geskiedenis van verhoogde bloeddruk en diabetes mellitus te bepaal; om jou ervarings rakende fisieke aktiwiteitsdeelname te ondersoek en hoe dit jou beïnvloed as gevolg van jou TSCI; en om jou omvang van sosiale en gemeenskapsherintegrasië te ondersoek en die faktore wat jou een jaar na besering beïnvloed.

Sal my deelname aan hierdie studie vertroulik gehou word?

Ons sal ons bes doen om u persoonlike inligting vertroulik te hou. Om u vertroulikheid te beskerm, sal u naam en ander belangrike inligting verskaf word. Besonderhede van enige inligting wat verskaf word, sal streng vertroulik gehou word. Data wat ingesamel word, sal in 'n pasgemaakte rekenaar en ander redigeer toestelle gehou word.

As ons 'n verslag of artikel oor hierdie navorsingsprojek skryf, sal u identiteit soveel moontlik beskerm word.

Wat is die risiko's van hierdie navorsing?

Daar is geen bekende risiko's verbonde aan deelname aan hierdie navorsingsprojek nie. Beradingsdienste sal egter vir u beskikbaar wees as u hulle as gevolg daarvan benodig om aan die navorsingsprojek deel te neem.

Wat is die voordele van hierdie navorsing?

Hierdie navorsingsprojek sal noodsaaklike kennis verskaf aan die risikoprofiel van kliënte met traumatale rugmurgbeserings vir chroniese siektes van lewenstyl (CDL) en beklemtoon die belangrikheid van bewustheid om te screening vir CDL-besering. Dit sal die behoefte aan 'n gekoördineerde gesondheidsorgstelsel en verbeterde kommunikasie tussen verskillende regeringsektore verlig, asook die toewysing van hulpbronne vir hierdie gemarginaliseerde bevolking.

Moet ek in hierdie navorsing wees en mag ek op enige stadium ophou deelneem?

U deelname aan hierdie navorsing is heeltemal vrywillig. U mag kies om glad nie deel te neem nie. As u besluit om aan hierdie navorsing deel te neem, kan u enige tyd ophou deelneem. As u besluit om nie aan hierdie studie deel te neem nie, of as u op enige stadium ophou deelneem, sal u nie enige voordele wat u andersins kwalifiseer, gepenaliseer of verloor word nie.

Is daar enige hulp beskikbaar as ek negatief geraak word deur deelname aan hierdie studie?

U sal na toepaslike gesondheidswerkers verwys word indien daar tydens die verloop van die studie 'n verwysing nodig is.

Wat as ek vrae het?

Hierdie navorsing word uitgevoer deur Marc Naidoo van die Fisioterapie Departement, Universiteit van Wes-Kaapland. As u vrae het oor die navorsingstudie self, kontak my asseblief by: Departement Fisioterapie, Universiteit van Wes-Kaap,

Privaatsak X17, Bellville 7535, Suid-Afrika of 0729082908, e-pos:
marc.anton.naidoo@gmail.com.

Indien u enige vrae rakende hierdie studie en u regte as 'n navorsingsdeelnemer het of as u enige probleme rakende die studie aangemeld het, kontak asseblief:

Departementshoof: Prof Anthea Rhoda

Universiteit van die Wes-Kaap

Privaatsak X17

Bellville 7535

Dekaan van die Fakulteit Gemeenskaps- en Gesondheidswetenskappe: Prof J. Frantz

Universiteit van die Wes-Kaap

Privaatsak X17

Bellville 7535



Hierdie navorsing is deur die Universiteit van Wes-Kaap se Senaat Navorsingskomitee en Etiekkomitee goedgekeur

Appendix 8 isiXhosa participant information sheet



UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-9592542, Fax: 27 21-9591217
E-mail: marc.anton.naidoo@gmail.com

INKCUKACHA YENGCACISO YENGCACISO

Isihloko seProjekthi: "Umngcipheko wezifo ezingapheliyo zokuphila emva kokulimala kwentambo yomgudu eKapa Metropolitan"

Yintoni esi sifundo?

Le projekthi yophando eyenziwa nguMarc Naidoo kwiYunivesithi yeNtshona Koloni. Injongo ephambili yale projekthi kukuvavanya nokuphonononga imfuneko yokungenelela kwe-CVD emva kokugcina ukulimala kwentambo yomgudu kummandla waseMzantsi Afrika wendawo. Ndingathanda nokufumanisa indlela ova ngayo okanye ukuqonda ukubuyiswa kwakho kwakhona kuluntu ukusuka kumbono womsebenzi.

Ndiya kucelwa ukuba ndenze ntoni ukuba ndivuma ukuthatha inxaxheba?

Siyakukucela ukuba uphendule imibuzo ehlobene nokulimala komnxeba; isifo sakho esingapheliyo kwiprofayili yokuphila; ukugqiba ukuziphatha kwakho kwengozi ekuxhomekeke kwiingozi ze-CVD; ukucacisa imbali yakho yokunyuswa kwengcinezelo yegazi kunye nesifo sikashukela; ukuphonononga amava akho malunga nokuthatha inxaxheba komzimba kunye nendlela ekuchaphazela ngayo ukulandela i-TSCI yakho; kwaye uhlolisise ubungakanani bakho bokuhlaziywa kwentlalo kunye noluntu kunye neemeko ezikuchaphazela ukulimala kwithuba elilodwa lonyaka.

Ngaba ukuthatha inxaxheba kwam kulesi sifundo kuya kugcinwa ngasese?

Siza kwenza konke okusemandleni ethu ukugcina ulwazi lwakho luyimfihlo. Ukukunceda ukukhusela igama lakho kunye nolunye ulwazi olubalulekileyo luya kubhalwe. Iinkcukacha zaluphi na ulwazi olunikeziweyo luya kugcinwa

ngokuyimfihlo. Idatha eqokelelwayo iya kugcinwa kwikhompyutheni ebhaliweyo kunye namanye amacebo okugcina.

Ukuba sibhala ingxelo okanye inqaku malunga nale projekthi yophando, ubume bakho buya kukhuselwa kumlinganiselo ophezulu.

Ziziphi iingozi zale phando?

Akukho zingozi eziyaziwayo ezichaphazelekayo nxaxheba kule projekthi yophando. Nangona kunjalo, iinkonzo zokunika iingcebiso ziya kufumaneka kuwe ukuba kufuneka uzifune ngenxa yesigqibo sokuthatha inxaxheba kwiprojekthi yophando.

Ziziphi iingenelo zale phando?

Le projekthi yophando iya kunika ulwazi olubalulekileyo kwiprofayili yengozi yabathengi abanobungozi obunzima bokugula ngenxa yezifo ezingapheliyo zokuphila (CDL) nokugqibisa ukubaluleka kokwazisa ukujonga ukulimala kwe-CDL post. Oku kuya kukhanyisa imfuno yenkqubo yokunakekelwa kwempilo kunye nokuphuculwa kolonxibelelwano phakathi kwamacandelo ahlukeneyo karhulumente kunye nokulungelelanisa ukwabiwa kwezibonelelo kulolu hlobo lwabantu abahlukeneyo.

Ngaba kufuneka ndibe kuloluphando kwaye ndivumelekile ukuyeka ukuthatha inxaxheba nanini na?

Ukuthatha inxaxheba kwakho kule phando ngokuzithandela ngokupheleleyo. Unokukhetha ukuba ungathathi nxaxheba kukho konke. Ukuba uthatha isigqibo sokuthatha inxaxheba kulolu cwaningo, unokuyeka ukuthatha inxaxheba nanini na. Ukuba uthatha isigqibo sokuba ungathathi inxaxheba kulolu cwaningo okanye ukuba unqamle ukuthatha inxaxheba nangaliphi na ixesha, awuyi kuhlawulwa okanye ulahlekelwe nayiphi na inzuzo apho uyafaneleka.

Ngaba kukho uncedo olukhoyo xa ndichaphazeleka kakubi ngokuthatha inxaxheba kwesi sifundo?

Uya kuthunyelwa kubasebenzi bezempilo abafanelekileyo ukuba kukho imfuneko yokuthunyelwa ngexesha lokufunda.

Kuthekani ukuba ndinemibuzo?

Olu phando luqhutywa nguMarc Naidoo weSebe lePhysiotherapy, iYunivesithi yeNtshona Koloni. Ukuba unemibuzo malunga nokuhlola ngokwayo, nceda uqhagamshelane nam: kwiSebe lePhysiotherapy, iYunivesithi yeNtshona Koloni, Private Bag X17, Bellville 7535, South Africa okanye 0729082908, imeyile: marc.anton.naidoo@gmail.com.

Ngaba unayo nayiphi na imibuzo malunga nale sifundo kunye namalungelo akho njengomdla-nxaxheba okanye ukuba unqwenela ukubika nayiphi na ingxaki oye wahlangabezana nayo ngokumalunga nophando, nceda qha ga mshelana:

INTloko yeSebe: UProfhea u-Anthea Rhoda

KwiYunivesithi yeNtshona Koloni

Private Bag X17

EBellville 7535

I-Dean ye-Faculty yoLuntu kunye neSayensi yezeMpilo: uProf. J. Frantz

KwiYunivesithi yeNtshona Koloni

Private Bag X17

EBellville 7535



Olu phando luvunyiwe yiKomidi yeNtshona Koloni yeNkcazo yoPhando kunye neKomiti yeeNtetho.

Appendix 9 ISCoS basic data set, Core Form

**INTERNATIONAL SPINAL CORD INJURY DATA SET
CORE DATA SET COLLECTION FORM**

Dates (YYYYMMDD)

Birth date _____ / _____ / _____

Injury date _____ / _____ / _____

Acute Admission _____ / _____ / _____

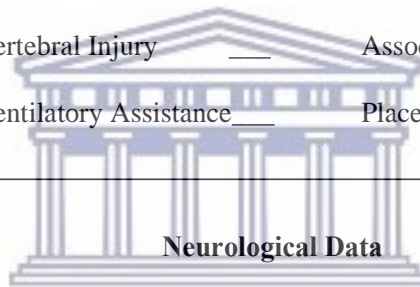
Final Inpatient Discharge _____ / _____ / _____

Total Days Hospitalized _____

Gender _____

Injury Etiology _____ Vertebral Injury _____ Associated Injury _____

Spinal Surgery _____ Ventilatory Assistance _____ Place of Discharge _____



Neurological Data

Acute Admission

Final Inpatient Discharge

Date of Exam

Date of Exam

_____ / _____ / _____

_____ / _____ / _____

Sensory level
Left Right

Sensory level
Left Right

Motor level
Left Right

Motor level
Left Right

ASIA Impairment Scale

ASIA Impairment Scale

Appendix 10 American Spinal Cord Injury Association Impairment Scale (AIS)



Patient Name _____ Date/Time of Exam _____

Examiner Name _____ Signature _____

RIGHT		MOTOR KEY MUSCLES	SENSORY KEY SENSORY POINTS		SENSORY KEY SENSORY POINTS		MOTOR KEY MUSCLES	LEFT	
			Light Touch (LTR)	Pin Prick (PPR)	Light Touch (LTL)	Pin Prick (PPL)			
		C2					C2		
		C3					C3		
		C4					C4		
		C5					C5	Elbow flexors	
		C6					C6	Wrist extensors	
		C7					C7	Elbow extensors	
		C8					C8	Finger flexors	
		T1					T1	Finger abductors (little finger)	
		T2					T2		
		T3					T3		
		T4					T4		
		T5					T5		
		T6					T6		
		T7					T7		
		T8					T8		
		T9					T9		
		T10					T10		
		T11					T11		
		T12					T12		
		L1					L1		
		L2					L2	Hip flexors	
		L3					L3	Knee extensors	
		L4					L4	Ankle dorsiflexors	
		L5					L5	Long toe extensors	
		S1					S1	Ankle plantar flexors	
		S2					S2		
		S3					S3		
		S4-5					S4-5		
		(VAC) Voluntary Anal Contraction (Yes/No)					(DAP) Deep Anal Pressure (Yes/No)		
		RIGHT TOTALS (MAXIMUM)	(50)	(56)	(56)	(56)	LEFT TOTALS (MAXIMUM)		
		MOTOR SUBSCORES			SENSORY SUBSCORES				
		UER <input type="text"/> + UEL <input type="text"/> = UEMS TOTAL <input type="text"/>			LTR <input type="text"/> + LTL <input type="text"/> = LT TOTAL <input type="text"/>				
		MAX (25) (25) (50)			PPR <input type="text"/> + PPL <input type="text"/> = PP TOTAL <input type="text"/>				
		MAX (25) (25) (50)			MAX (56) (56) (112)				
		LER <input type="text"/> + LEL <input type="text"/> = LEMS TOTAL <input type="text"/>			PPR <input type="text"/> + PPL <input type="text"/> = PP TOTAL <input type="text"/>				
		MAX (25) (25) (50)			MAX (56) (56) (112)				
		NEUROLOGICAL LEVELS			4. COMPLETE OR INCOMPLETE? <input type="text"/>				
		Steps 1-5 for classification as on reverse			Incomplete = Any sensory or motor function in S4-5				
		1. SENSORY <input type="text"/> R <input type="text"/> L <input type="text"/>			5. ASIA IMPAIRMENT SCALE (AIS) <input type="text"/>				
		2. MOTOR <input type="text"/> R <input type="text"/> L <input type="text"/>			(In complete injuries only)				
					ZONE OF PARTIAL PRESERVATION				
					Most caudal level with any innervation				
					SENSORY <input type="text"/> R <input type="text"/> L <input type="text"/>				
					MOTOR <input type="text"/> R <input type="text"/> L <input type="text"/>				

This form may be copied freely but should not be altered without permission from the American Spinal Injury Association.

REV 11/15

Appendix 11 WHO STEPwise instrument

CARDIOVASCULAR DISEASE PREVENTION QUESTIONNAIRE

- This questionnaire is about risks for cardiovascular diseases
- This questionnaire is **completely voluntary**. You may choose not to participate or not to answer any specific question. You may skip any question you are not comfortable in answering.
- This questionnaire is **completely anonymous**. Please make no marks of any kind on the survey which could identify you individually.
- Composite data will be used to develop a health promotion programme.



INSTRUCTIONS UNIVERSITY of the WESTERN CAPE

- Select only one response, unless instructed otherwise.
- Please tick the appropriate answer e.g. ✓ or circle one correct answer where indicated

Thank you very much for your co-operation

THE FOLLOWING QUESTIONS ASK ABOUT YOUR DEMOGRAPHIC CHARACTERISTICS

Q1. Age: ___ years old

Q2. Gender:

- male female

Q6. Ethnic origin/race:

- African/Black Coloured White
 Indian/Asian other (specify) _____

Q7. Marital status:

- never married married / domestic partner separated/divorced
 widowed



Q8. Highest level of education:

- no schooling some primary school primary school completed
 some secondary school secondary school completed some tertiary education
 tertiary education completed

Q9. Where do you live most of the year?

- your own home / flat home of a friend / family member
 retirement home nursing home
 Other (specify) _____

Q10. How many people live with you?

- I live alone
- 1 person
- 2 persons
- 3 persons
- 4 persons
- 5 or more persons

Q11. Location of your house:

- urban
- rural

Q12. Your current employment status:

- working full-time (40 hours or more a week)
- unemployed
- working part-time (less than 40 hours a week)
- pensioner
- other (specify) _____

THE FOLLOWING QUESTIONS ASK ABOUT VARIOUS HEALTH BEHAVIOURS

Q13. Have you ever smoked in your life?

- Yes
- No

Q14. How old were you when you first started smoking?

_____ years old

Q15. Have you smoked in the past 30 days?

- Yes
- No

Q16. On average how many do you smoke each day?

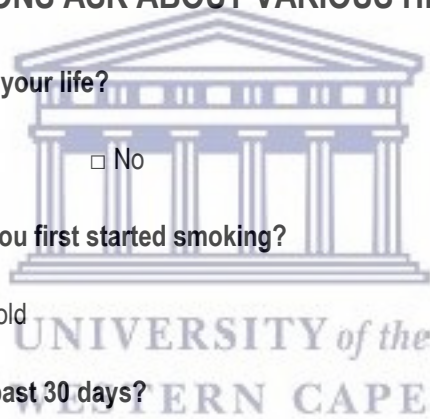
Q17. Have you ever consumed an alcoholic drink such as beer, wine, spirits?

- Yes
- No

Q18. During the past 30 days have you consumed an alcohol drink such as beer, wine or spirits?

- Yes
- No

Q19. During the past 30 days, on how many occasions did you have at least one alcoholic drink?



Q20. During the past 30 days, when you drank alcohol, on average how many standard alcoholic drinks did you have on one occasion?

THE NEXT SECTION ASKS ABOUT YOUR HISTORY OF RAISED BLOOD PRESSURE

Q21 Have you ever had your blood pressure measured by a doctor or health worker prior to your injury?

Yes No

Q22 Have you ever been told by a doctor or health worker that you have raised blood pressure or hypertension?

Yes No

Q23 If you have answered yes to Q22: Have you received any of the following treatments/advice for high blood pressure by a doctor or health worker?

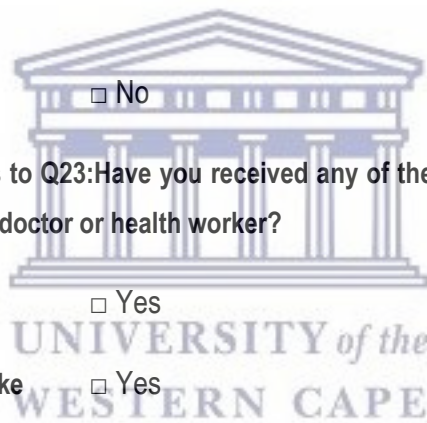
Medication: Yes No

Advice to reduce salt intake Yes No

Advice to lose weight Yes No

Advice to stop smoking Yes No

Advice to do more exercise Yes No



PHYSICAL MEASUREMENTS AND MEDICAL FILE INFORMATION:

BLOOD PRESSURE:

Reading 1: Systolic _____ mmHg Diastolic _____ mmHg

Reading 2: Systolic _____ mmHg Diastolic _____ mmHg

Reading 3: Systolic _____ mmHg Diastolic _____ mmHg

HEART RATE:

Reading 1: Beats per minute _____

Reading 2: Beats per minute _____

Reading 3: Beats per minute _____

Blood glucose: Fasting blood glucose _____ mmol/l

Total cholesterol: _____ mmol/l



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