

**PHYSICAL ACTIVITY AFTER SPINAL CORD INJURY:  
EXPLORING EXPERIENCES IN THE CAPE  
METROPOLITAN AREA.**

**BY**

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**UNIVERSITY of the  
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**KEY WORDS**

Physical activity

Barriers

Facilitators

Spinal cord injury

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Explore

Secondary complications

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Photo-voice focus groups

Health indicators

Socio- economic



## ABSTRACT

A spinal cord injury (SCI) is an acquired injury, by which damage to the spinal cord causes complete or partial neurological impairment. The major causes of premature death after a spinal cord injury have been documented as septicaemia, urinary tract infections and respiratory disorders. However since the development of modern, comprehensive, medical care, persons with spinal cord injuries generally live longer and thus age with their disability. Several researchers have reported on physical activity and people with SCI and the benefits of it. The overall aim of this study is to explore and describe the experiences of community dwelling survivors of spinal cord injuries regarding their involvement in physical activity or exercise in their respective communities. This was a descriptive and exploratory study that utilised a qualitative approach. Participants for this study were mainly recruited from a registry kept by a not-for-profit organization rendering services and support to survivors of spinal cord injuries in the Cape Metropolitan area. Furthermore, the use of the photo-voice technique was deemed appropriate for this study as this would allow the participants to depict their experiences of physical activity/exercises in their respective communities by means of photographs. Five themes were generated from the thematic analysis: *Knowledge of the benefits of physical activity or exercise; getting to and from facilities for physical activity or exercise; availability of facilities; influence of weather and future plans regarding involvement in physical activity.* The findings of this study was that most of the participants were aware of the importance of physical activity and the majority was 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, which was highlighted by emerging themes. Permission and ethics clearance was obtained from Senate Higher Degree and Research Committee of the University of the Quad-Para Association of South Africa. Participation in this study was voluntary and confidentiality and anonymity was assured. Participants were also assured of their right to participate, decline or withdraw at any time without any implications. In case of any complaint, the participant will be referred for appropriate intervention. An informed written consent was completed by every participant who agreed to take part in the study. All participants were treated with dignity and respect and feedback will be given to all relevant bodies.

## DECLARATION

I hereby declare that “**Physical activity after spinal cord injury: Exploring experiences in the Cape Metropolitan area**” is my own work, that it has not been submitted for any degree or examination at any other university, and that all the sources used or quoted have been indicated and acknowledged by complete references.

Brent Martin

Signature .....

August 2017



Witness .....

Professor J. Phillips

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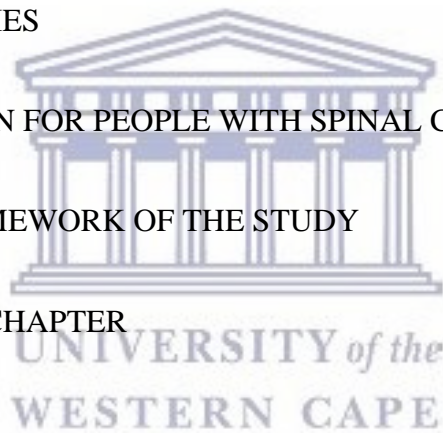
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## CHAPTER ONE

### INTRODUCTION

#### **1.1 Introduction to the chapter**

The study attempted to explore the experiences of community-dwelling survivors of spinal cord injuries (traumatic and non-traumatic spinal cord injuries) with regards to their involvement in physical activity or exercise. This introductory chapter provides an overview of the importance of physical activity for survivors of spinal cord injuries generally. The problem statement highlights the lack of physical activity among survivors of spinal cord injuries even though the importance of physical activity has been reported globally. The overall aim, specific objectives and significance of the study are also outlined in this chapter.

#### **1.2 Background to the study**

A spinal cord injury (SCI) is an acquired injury, by which damage to the spinal cord causes complete or partial neurological impairment. The damage can be acquired through a traumatic (TSCI) or non-traumatic (NTSCI) process. Spinal cord injuries lead to disability as result from the trauma to the spinal cord, and it presents in a very individualised and patient-specific manner (Rauch, Baumberger, Moise, von Elm & Reinhardt, 2011). The major causes of premature death after a spinal cord injury have been documented as septicaemia, urinary tract infections and respiratory disorders (De Vivo, Black & Stover, 1993). However since the development of modern, comprehensive, medical care, persons with spinal cord injuries generally live longer and thus age with their disability. Conditions associated with an increase in mortality in later life, e.g. diabetes

mellitus, tobacco addiction, hypertension, cardiovascular disorders and lifestyle related cancers, have been identified in South Africa to be influenced by behavioural factors (Peltzer, Mashego & Mabeba, 2003). It is therefore assumed that young adults with spinal cord injuries are also at risk as is the general population.

Studies across the world has shown that physical activity improves the quality of life of able-bodied people as well as people with SCI (Kehn & Kroll, 2009). They further reported that physical activity for individuals with spinal cord injuries increases quality in life, boost energy, even improves self-confidence and body image. Physical activity was identified as one of the key health indicators and health objectives in people with SCI, but research has shown that they are still less active than able-bodied people (Van der Berg-Emons et al, 2008). Kehn and Kroll (2009) reported that people with SCI are more at risk to illnesses and secondary conditions (e.g. urinary tract infections, pressure ulcers, diabetes, cardiovascular diseases, obesity, osteoporosis and arthritis) because they are less physically active compared to able-bodied people. Scelza, Kalpakjian, Zemper, and Tate (2005) reported that cardiovascular health is a major concern in individuals with SCI and heart disease was found to be one of the leading causes or contributions of death for these individuals. Obesity has also been identified as a major contributing factor. Furthermore they reported that health promotion for other individuals with disabilities, which include survivors of SCI, have focus more on primary condition prevention, than on secondary condition prevention.

Strauss, Devivo, Paculdo and Shavelle (2006) reported that acute mortality rates for people with SCI have declined over the past three decades due to an increase in

focus on the prevention of secondary conditions and complications. They established that people with SCI are at a high risk for medical complications and secondary chronic conditions and physical activity can prevent such conditions. Due to the longer life expectancy of those living with and surviving spinal cord injury, health problems related to aging start to come into play (Scelza et al, 2005). Kehn and Kroll (2009) reported that a number of authors have reported the beneficial effects of physical activity (exercise, sports) and it further improved the level of fitness in people with SCI. Kehn and Kroll, (2009) further reported that physical activity enhances functional abilities and increases quality of life and social integration for those living with a SCI.

Post injury physical activity or sports participation for individuals with SCI has many benefits such as reducing clinical depression disease; re-hospitalization improve family and social interaction and prolong life expectancy (Williams & Wu, 2000). Tasiemski, Bergstrom, Savic and Gardner (2000) demonstrated that involvement of sports by wheelchair users improved rehabilitation, increased independence and gave them self-confidence. Involvement in sports or physical activities also gave them inspirations for further development. Levins, Redenbach and Dyck, (2003) stated that endurance training with people with SCI improves exercise performance similar to able-bodied people.

For people with and surviving SCI to participate in physical activity they have to overcome many obstacles/barriers. Kehn and Kroll (2009) identified several barriers to exercise; this including accessibility, pain, cost, psychological barriers and also a lack of

motivation, energy and a lack of logistical information. Furthermore the level of injury can also be identified as a detriment to physical activity. Perceived behavioural control and health complications could also be seen as a barrier to physical activity. Levins, et al (2004) stated that although the positive effects of physical activity was well documented; barriers for physical activity have been examined in the general public, but if it was relevant to the SCI population was questionable. Despite the amount of research that was done in the general field of physical activity, little is known regarding the barriers to physical activity for those with and surviving SCI (Levins, et al 2004). They emphasize the reasons for failing to incorporate physical activity into the general population. Studies have shown that time constraints, lack of motivation or “laziness” to be the prime reasons in the general population, which is in stark contrast to the barriers for individuals with SCI. These limitations are often attributed to their disability and inability to perform physical activities that promote health. More recently researchers have questioned these assumptions (Levins et al 2004). As outlined earlier the importance of physical activity is clear but the event of a disabling condition such as a spinal cord injury can pose a serious challenge to staying physically active. For health professionals it is thus important to understand the factors influencing physical activity participation among individuals with spinal cord injuries.

### **1.3 Problem statement**

Studies highlighted the importance of physical activity in people with spinal cord injuries and how the perceived barriers or facilitators could influence their participation in physical activity after spinal cord injury (Levins, Redenbach, and Dyck, 2003;

Williams & Wu, 2000). These researchers have alerted to benefits of physical activity such as improved rehabilitation and increased independence. However barriers influencing participation in physical activity has also been described such as lack of motivation for example (Kehn & Kroll, 2009). It also highlighted the benefits of physical activity by preventing secondary conditions after spinal cord injury. However limited research has been done on the experiences of spinal cord injury survivors with physical activity in South Africa, especially the Western Cape. For this reason this study will be to explore the experience of physical activity in people after a spinal cord injury and factors that influence the inability to participate in physical activity.

#### **1.4 Research Question**

What are the experiences of community dwelling survivors of spinal cord injuries with regards to their involvement/participation in physical activity or exercise in their communities?

#### **1.5 Overall Aim**

The overall aim of this study is to explore and describe the experiences of community dwelling survivors of spinal cord injuries regarding their involvement in physical activity or exercise in their respective communities.

#### **1.6 Specific objectives**

The specific objectives of the study are as follows:



- To explore and describe the participation of community dwelling survivors of spinal cord injuries in physical activity or exercise.
- To explore and describe the facilitators and barriers to participation in physical activity or exercise in communities as experienced by community dwelling survivors of spinal cord injury.
- To explore and describe the future plans of community dwelling survivors of spinal cord injuries with regards to involvement in physical activity or exercise.

### **1.7 Significance of the study**

The benefits of physical activity for people with SCI have been widely researched in other countries. It has been done in more or less affluent areas across the world.

Very little studies were done in South Africa and very little or nothing in Western Cape. The Western Cape has been labelled as one with several areas where gangsterism and unemployment rates are extremely high. In line with this the population of spinal cord injuries (SCI) in South Africa and the Western Cape specifically are predominantly male with a perceived poor socio-economic background, and the injury caused by acts of violence. This study will give an insight on the knowledge of the benefits of physical activity and which barriers are largely perceived as the main factors contributing to the lack of physical activity. This study could also provide a greater insight into the need for physical activity promotion among survivors of spinal cord injuries in the Cape Metropolitan areas. This study can also be a catalyst to further studies into structured physical activity programs in this area in the future.

## 1.8 Definition of terms used in this study

**Barriers:** One's opinion of the tangible and psychological costs of the advised or recommended action (Glanz, 1998).

**Chronic diseases of lifestyle/Non- communicable diseases:** These are diseases which are classified as non-infectious, as they cannot be transmitted onto others, and include diseases such as cancer, diabetes mellitus, hypertension, and cardiovascular diseases. In this study non-communicable diseases will mainly refer to hypertension and diabetes (Tsolekile, 2007).

**Disability:** Is any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered typical for a human being (Chase, Cornille & English, 2000). In the International Classification of Functioning, Disability and Health (ICF) (2001), the term disability serves as an umbrella term for impairments, activity limitations or participation restrictions.

**Lifestyle:** Lifestyle comprises the aggregate of an individual's actions and behaviours of choice, which can affect health-related fitness and health status (Bouchard, Shephard & Stephen, 1993).

**Physical activity:** Is defined as "bodily movement produced by skeletal muscles that requires energy expenditure" and may bring about physical fitness and health related

benefits (Cooper, Quatrano, Axelson, Harlan, Stineman, Franklin, Krause, Bach, Chambers, Chao, & Alexander, 1999).

**Quality of life:** The definitions and descriptions of quality of life include both objective (income, living situations and physical functioning) and subjective (individual's perception of important life domains and satisfaction with those domains) indicators of physical and psychological phenomena (Stuifbergen & Rogers, 1997).

**Spinal cord injury:** Is defined as permanent paralysis, to a greater or lesser extent, as a result of damage to the spinal cord. Depending on the level of injury, the paralysis is described as tetraplegia (or quadriplegia) referring to all four extremities (both the arms and legs) affected, and paraplegia referring to paralysis in the lower part of the body from approximately the waist down (Hampton & Marshall, 2000). Furthermore a spinal cord injury can be classified depending on the cause of damage, i.e. damage can be acquired through a traumatic (**traumatic spinal cord injury**) or non-traumatic (**non-traumatic spinal cord injury**) process. Spinal cord injuries can also be categorised as an "complete:" spinal cord injury which results in the complete loss of function below the point of injury and incomplete spinal cord injury which results in some feeling or movement will still be evident below the point of injury.

**Community dwelling survivors:** individuals with a spinal cord injury, living in their respective communities after discharge.

## 1.9 Abbreviations used in the study

<b>CVD:</b>	Cardiovascular diseases
<b>DPO:</b>	Disabled People's Organisation
<b>ICF:</b>	International Classification of Functioning, Disability and Health
<b>NTSCI:</b>	Non-traumatic spinal cord injury
<b>QASA:</b>	Quad Para Association of South Africa
<b>TSCI:</b>	Traumatic spinal cord injury
<b>SCI:</b>	Spinal cord injury
<b>UWC:</b>	University of the Western Cape
<b>WHO:</b>	World Health Organisation

## 1.10 Outline of the thesis

**Chapter one** provides the background of the study. An overview of the importance of physical activity for individuals with spinal cord injuries is outlined. The background information highlighting the barriers to participation in physical activity experienced by individuals with spinal cord injuries are also highlighted. The significance, aims and objectives of the study are presented. The chapter concludes by providing an outline of the thesis.

**Chapter two** presents a review of literature that is relevant to this study. Literature pertaining to the incidence and prevalence of spinal cord injuries are reviewed. Furthermore literature highlighting the

barriers to and facilitators of physical activity for individuals with spinal cord injuries is reviewed. Lastly, a theoretical framework for the study is described.

**Chapter three** provides the methodological issues of the study. The research setting, study population and sampling, inclusion criteria and study designs are described. The photo-voice methodology that was used in this study is described in detail. The analysis that was used is described too. The chapter ends with an explanation of the ethics that guided the study.

In chapter **four**, the results from the focus group discussions are presented. A description of the participants of the study is firstly provided. The results, i.e. the themes that emerged from the data analysis are presented in this chapter and these themes are illustrated with verbatim quotes and pictures.

**Chapter five** presents a discussion of the findings of the study in comparison to previous research in the area.

**Chapter six** summarises the important points of the current study. Recommendations related to the findings are also proposed and the limitations of the study highlighted.

## CHAPTER TWO

### LITERATURE REVIEW

#### 2.1 INTRODUCTION

This chapter presents a review of literature that is relevant to this study. Firstly an overview of the epidemiology of spinal cord injuries is provided. The importance and or role of physical activity in the life of survivors of spinal cord injuries are highlighted with literature reviewed. Furthermore, literature highlighted the barriers and facilitators of physical activity for these survivors are reviewed. Lastly, a theoretical framework for the study is described.

#### 2.2 OVERVIEW OF THE EPIDEMIOLOGY OF SPINAL CORD INJURIES

The World Health Organisation (WHO) described a spinal cord injury as “a medically complex and life-disrupting condition” (WHO, 2013). It is a severe traumatic disability that occurs suddenly and mainly affecting young people (Hampton & Marshall, 2000; Morris & Marshall, 1997). It is an injury to the spinal cord situated within the spinal column and the damage to the cord could be either traumatic or non-traumatic (WHO, 2013). This type of injury is considered permanent and it has historically been associated with high mortality rates (WHO, 2013; O’Hare & Hall, 1997). Depending on the level and completeness of injury to the spinal cord it is described as quadriplegia or paraplegia (Wood-Dauphinee et al., 2002). Quadriplegia is the impairment or loss of motor and/or sensory function in the arms, trunk and legs while paraplegia is the impairment in the lower part of the body while the arm function is fully or partially spared (O’Hare & Hall, 1997; Bromley, 1998; Quadriplegic Association of South Africa, 2002-3).

In the early days of spinal cord injury care, the mortality rate for SCI was as high as 80% (WHO, 2013). With the rapid advancement in the medical and rehabilitation management of persons with SCI in the last few decades, the life expectancy of the survivors is almost similar to their able bodied counterparts. Bodner (2009) and Silver (2003) contributed the decline in mortality rates to the 2-hourly turning of patients, skin care, and improved bladder management. They further stated that the better functional outcomes could be attributed to physical and occupational therapy together with a more holistic approach to patient care, including their socio-economic needs.

### **2.2.1 Incidence and prevalence of SCI**

In order to provide an overview of the epidemiology of spinal cord injuries, one needs to look at the prevalence (i.e. the number of people living with SCI), the incidence (the number of new cases) and the causes thereof. Wyndaele and Wyndaele (2006) reported that the incidence and prevalence of spinal cord injury (SCI) is important because of their high personal bio-psychological impact and their high socio-economic consequences. The WHO stated that in 2013 there were no reliable global or regional estimates of SCI prevalence (WHO, 2013). Further to this Cripps et al, (2011) also reported that insufficient data existed on global prevalence for people with SCI although incidence studies were done globally.

In their comprehensive report on SCI, the WHO provided some information on the prevalence of spinal cord injuries for six countries. The prevalence figures ranged from 280 per million (Finland) to 1298 per million population (Canada) (WHO, 2013). The methods of

collecting this data also ranged from prospective or retrospective cross-sectional designs to retrospective longitudinal designs; and from registry of hospital data to national registries.

Global literature comparisons of the incidence of SCI have been reported in the early 2000's (Wyndaele & Wyndaele, 2006; Ackery, Tator & Krassikov, 2004). Wyndaele and Wyndaele (2006) reported that the incidence of spinal cord injuries (SCI) all over the world varies from 10.4 and 83 cases per million per year. Studies in the United Kingdom reported spinal cord injury incidence to be 1200 each year and 40 000 currently living with the disability (Kennedy, Cox & Mariani, 2012). Cohen, Marino, Sacco and Terrin (2012) reported that an estimated 11 000 individuals in the United States experience spinal cord injuries a year. Both Ackery et al. (2004) and Wyndaele and Wyndaele (2006) noted the need for standardized reporting of people with spinal cord injuries. Robertson, Bucks, Skinner, Allison and Dunlop (2011) reported an incidence of approximately 300 – 400 per annum with aged standardized incidence of 15 per million. They further reported that in the remote areas of Western Australia the incidence of SCI was the highest. The differences observed in the study above could be due to the different study designs, such as prospective vs retrospective; longitudinal vs cross-sectional; and the use of hospital registers vs population based registers.

Very limited information regarding the incidence of spinal cord injuries is available for continents such as Latin America, Asia and Africa (Lee, Cripps, Fitzharris & Wing, 2014; Vasiliadis, 2012). In the first prospective, population-based study done in the Western Cape in South Africa, an incidence rate of 75 per million population was found (Joseph, Delcarme, Vlok, Wahman, Phillips, Nilsson Wikmar, 2015). This incidence rate is among the highest in



the world, with a high male to female ratio with most of the survivors between the ages of 18 and 29 years and of a poor socio-economic background.

### **2.2.2 Causes of spinal cord injuries**

The causes of spinal cord injuries could be due to a traumatic (TSCI) or non-traumatic (NTSCI) event. The WHO reported that based on available evidence on the various causes of TSCI from all the regions, the most common causes are transport related (road traffic accidents particularly), falls and violence (WHO, 2013). The WHO (2013) further reports that road traffic accidents accounted for almost 70% of the SCI cases in the African region, and ranges from 40% in South-East Asia to 55% in the Western Pacific region. Falls accounted for over 40% of all the cases in the Eastern Mediterranean and South East Asia regions and were mainly the result of falls from trees while cutting leaves. The proportion of SCI as a result of violence varies greatly but the Americas, African and Eastern Mediterranean Regions reported the highest percentages.

Joseph et al. (2015) reported that the cause of injury for the overwhelming majority of the participants in their study was due to assault (approximately 60%). On further investigation of the assault category, these participants sustained their injuries by gunshots (52%), stab wounds (33%) and interpersonal violence (15%). These authors further reported that assault as a cause for injury was significantly more the case for males as opposed to females.

Very few reliable national data concerning the causes of NTSCI is available but some of the studies suggest that the leading causes are neoplastic tumours and degenerative conditions of the spinal column, vascular and autoimmune disorders (WHO, 2013).

The sections on both the incidence and prevalence as well as the causes of spinal cord injuries in the sections above clearly illustrates that most of the studies were done in the more developed regions of the world. It is clearly highlighted that regions such as Africa provides little information with regards to the incidence and prevalence of spinal cord injuries. It is also clear that the incidence and prevalence reported differs greatly from region to region but this could be due to the methodological differences between studies. As far as the causes of spinal cord injuries are concerned, the literature reviewed pointed to transport related incidents as causes for the majority of the cases. In the one study reviewed in Africa, it was highlighted that assault was the major cause of spinal cord injuries in South Africa.

### **2.3 PHYSICAL ACTIVITY AND SCI**

Research has shown that people with SCI are also at risk of the same chronic diseases such heart disease, stroke and diabetes as the general population (Wahman et al., 2010; Bauman & Spungen, 2008; Myers, Lee & Kiratli, 2009). These researchers further postulate that these chronic health conditions in people with SCI are linked to the changes in their body composition, such as a decreased muscle mass and to the lower levels of physical activity as a result of their paralysis. In recognizing this, it is evident that people with SCI also require access to mainstream services such as health promotion and involvement in physical activity since these chronic health conditions are strongly related to reduced physical activity (Fekete

& Rauch, 2012; Ditor, Latimer, Martin Ginis, Arbour, McCartney & Hicks 2003). It has been noted that a significant proportion of individuals with spinal cord injuries are leading sedentary lifestyles (Nash, 2005) and the CVD risk of obesity (Weaver, Collins, Kurichi, Miskevics, Smith, Rajan, & Gater, 2007). In addition, impaired fasting glucose, insulin resistance, and diabetes mellitus have all been reported to be common after spinal cord injury (Meyers et al., 2009) and when clustered these risk factors are likely to contribute to a high prevalence of cardiovascular diseases in those with spinal cord injuries (Myers, 2009).

### **2.3.1 Benefits of physical activity for people with SCI**

Several researchers have reported on physical activity and people with SCI and the benefits of it. Van den Berg-Emons et al, (2008) reported that persons with SCI are often restricted in their performance of every day physical activities and that makes the person with SCI more at risk to a hypo-active lifestyle with detrimental effects on physical fitness, social participation and quality of life. Kehn et al, (2008) also reported that individuals with SCI reported that physical activity increases quality of life, energy, self- confidence and body image. It was also reported that individuals use physical activity as a reason to stay healthy and fit.

Tasiemski, Kennedy, Gardner and Blaikely (2004) reported that physical activity in people with spinal cord injuries could be a catalyst for facilitating social integration. The same study reported that sports participation could counteract loss of confidence and mental in-activity. Sports participation by wheelchair users improves their rehabilitation outcome, increases their independence, gives them greater self-

confidence, improves quality of life. Tasiemski et al, (2000) and Levins et al, (2004) reported that people with spinal cord injuries (SCI) involved in wheelchair sports are more successful in avoiding major medical complication and hospitalization. Robertson et al, (2011) reported that in the absence of effective drug therapy, physical activity improves physical health activities of daily living, psychological well-being and quality of life in the SCI community. Scelza et al, (2005) reported that physical activity improves functional capacity, bone density in the upper limb, endurance, muscle strength, pain and psychological well-being and reduces stress. Tasiemski et al, (2004) reported that the most common reason for people with SCI participating in sport were to maintain a good physical condition and improving upper strength. Kehn and Kroll (2009) reported that individuals with SCI reported that physical activity increases quality of life, energy, self- confidence and body image. It was also reported that individuals use physical activity as a reason to stay healthy and fit.

### **2.3.2 Factors influencing physical activity participation for people with SCI**

When people with SCI are released from tertiary care, they need to re-integrate into their community, while they attempt to maintain a high quality of life despite numerous physical and psychological social occupational and financial obstacles (Robertson et al 2011). Kehn and Kroll (2009) reported that people with spinal cord injuries' path to a physically active lifestyle is fraught with obstacles. They identified several barriers to physical activity which was also identified in prior studies such as pain, costs, psychological barriers, a lack of motivation and energy and a lack of logistical information. They also identified the completeness of level of injury as well as intentions and behavioral control as barriers. Robertson et al, (2011) reported that

both in the general population and individuals with SCI, barriers to exercise may be internal (lack of motivation) or external (not having facilities nearby). Several other studies also identified a lack of personal assistance and the perception that attaining benefits from physical activity would take too much time and energy as barriers (Robertson et al, 2011). It was further reported that a study found no difference in the number of reported barriers in individuals with mobility impairments in relation to degree of limitations, although the degree was not defined (Robertson et al, 2011).

Rimmer and colleagues reported that there was a difference in the reported barriers of women with disabilities and the general population in physical activity (Levins et al, (2004). Women with disabilities reported that cost, transportation and the lack of knowledge of a community or sports facility as the main barriers to physical activity. This was used from a list of barriers constructed by the authors.

Wu and Williams, (2000) looked at participants returning to sport as SCI and barriers that affected a decrease in sports / physical activity, was caused by a loss of cultivated skills and disruption of social relationships and their increase in dependency. Kehn and Kroll (2009) categorized people with SCI into exercise and non – exercise participants and what barriers they perceived that may lead to a lack of physical activity and how physical activity could facilitate them (pre-injury exercise experience, motivational triggers –constraints, socio-environmental resources / barriers). They made the assumption that pre – injury activity was not a good predictor for post – injury activity and couldn't be used as a motivation for a facilitator to physical activity. Both non – exercises and exercises regarded motivation as a barrier or constraint.

Socio – environmental resources was also identified as a barrier to non – exercises and facilitator to exercise. (Scelza et al, 2005) reported that the identification of barriers to physical activity may be the first step to reducing social barriers to facilitate participation in physical activity and improve health outcomes. Levins et al. (2004) reported that the social model developed in 1970's and 1980's examines the way society “disables” and disabled individual through social environmental and attitudinal barriers. They also stated that people with SCI may face architectural barriers but encounter discrimination in public and presumptions related to their physical activity based on people without disability.

### **2.3.3 Health promotion for people with spinal cord injuries**

Health promotion is a multidimensional concept that applies to all individuals regardless of age or disability (Fowler, 1997). The definition of health promotion as “activities directed toward increasing the level of wellbeing and actualizing the health potential of individuals, families and communities/societies,” is similar to the goal rehabilitation (Breslow,1999). The goal of rehabilitation is to assist an individual with a disability to gain independence and functional skills for use in activities of daily living (Kendall et al., 2003; Zacijek-Farber, 1998).

The 2012 World Report on Disability (WHO, 2012) highlighted that people with disabilities seek more care on both an outpatient and inpatient basis than those without disabilities. The report further showed that despite this, people with disabilities do not receive more care than those without disabilities however. It has been shown too that people with disabilities receive

less screening and preventive services than the general population (Lezzoni & O'Day, 2006). It is thus clear that people with SCI very often have unmet health needs once they have completed their rehabilitation period in hospitals or rehabilitation units (Munce et al., 2009). The WHO (2013) also stated that people with SCI often experience barriers to maintaining healthy lifestyles.

Hogan et al. (2000) concluded that community-based health promotion interventions are required to address the health promotion and physical activity needs of people with spinal cord injuries in order to prevent the onset of secondary disease processes. Researchers have however stated that health promotion for those with disabilities, including SCI have been directed at primary prevention of disability rather than prevention of secondary conditions (Rimmer et al., 2004). Evidence from developed countries further suggest that many individuals with a spinal cord injury are at risk for all-cause CVD but are not referred for standard treatment (Wahman et al., 2010). It is thus argued that if many CVD risk factors are prevalent in the general population, it is an important step to increase awareness about screening for CVD risk factors both before spinal cord injuries and at every possible check-up after. The annual check-ups may then present a unique opportunity to perform such screening, institute therapeutic lifestyle interventions, education about the need to adopt healthier lifestyles, including diet, exercise and behaviours as countermeasures to their risks.

From the literature reviewed above, it is clear that individuals with a spinal cord injury are also at risk for chronic diseases as their able-bodied counterparts, and therefore physical activity participation is equally important for them. The studies reviewed and available in the

literature is mostly from developed countries and therefore little is known of the factors influencing physical activity participation among these individuals in developing countries and specifically those in under-resourced areas.

#### **2.4 Theoretical framework of the study**

At international level, attempts have been made throughout history to understand the concept of disability through various disability models. Historically, disability has been regarded as a health and social welfare issue by the medical model. Treatment and or rehabilitation services were thus offered by health professionals and State and faith-based organisations provided welfare support (Disabled People South Africa, 2001). Disabled people were thus relegated to the “sick role” implying that may not be physically active or participate in sports. The social model however emerged as a new interpretation or approach to disability. This model was inspired by an understanding that impairments are not the main cause of the problems facing people with disabilities but that it is the way society responds to them as the oppressed minority (Disabled People South Africa, 2001). Strength of this model was that it recognized that disability is not the major barrier preventing people with disabilities from leading full lives and secondly that it advocates inclusion and integration of them into mainstream activities. This model focussed on all the problems faced by people with disabilities except physical activity and physical activity needs (Bonnie, 2004).

For this study in attempting to understand the experiences of individuals with spinal cord injuries with physical activity, it will be done with the Convention of the Rights of Disabled People (CRDP) and the International Classification of Functioning, Disability and Health (ICF) as frameworks. The CRDP explains disability as a human rights and development



issue while the ICF provides a description of disability in terms of functioning and disability (WHO, 2013). The CRDP outlines the rights of all people with disabilities, including those with SCI, with regards to political, social and economic rights. In the South African context, the 2001 South African Household Survey highlighted that large numbers of individuals with disabilities still live in areas where the infrastructure is poor (Statistics South Africa, 2001). Mpofo (2003) further indicated that most individuals with disabilities in South Africa are not reaching their full potential because their concerns are not address in economic and political theories. Article 6 of the Disability Rights Charter of South Africa also states that “Disabled people shall have the right to engage in sport and recreational activities and resources, such as sport facilities and financial assistance, as well as opportunities for participation shall be made available to support their initiatives in this regard” (Disability Rights Charter of South Africa, 2000). This is however an aspect that is often forgotten or neglected by service providers and most sports facilities are not easy accessible for people with physical disabilities (Wazikele, 2007).

As stated earlier the International Classification of Functioning, Disability and Health (ICF), has been used to explain disability and has been developed through a lengthy process involving academics, clinicians and people with disabilities (WHO, 2013). In the ICF, issues with human functioning are categorized in three areas: impairments, activity limitations, and participation restriction. Impairments are problems related to bodily functions or structure such as paralysis. Activity limitations are the difficulties experienced in carrying out activities such as walking or eating. Finally, participation restrictions are problems related to the involvement of individuals in any area of life such discrimination in transportation or employment.

The ICF recognizes that the determinants of disability are not only the underlying health conditions but also the environmental factors. Thus the ICF places challenges faced by people with disabilities beyond the effect of individual impairment, to relationships that this group has micro- and macro-level structures. Micro-level factors may include issues such as not engaging in physical activity, which increases their vulnerability to risk of chronic diseases of lifestyle. Macro-level factors include elements such as poverty, cultural beliefs and lack of or inadequate policies, all of which play a role in increasing this population's vulnerability to an increased risk of secondary complications and or risk of chronic diseases of lifestyle. It further recognizes that personal factors such as motivation and self-esteem have an influence on an individual's participation in society.

## **2.5 Summary of the chapter**

This chapter provided an overview of the relevant literature regarding spinal cord injuries, the benefits of physical activity for individuals with spinal cord injuries and the factors influencing physical activity. A theoretical framework for the study is also provided. The next chapter will outline the methods used to meet the objectives of the study.

## CHAPTER 3

### METHODS

#### 3.1 Introduction

This chapter outlines the methods and procedures used to collect data to meet the objectives of this study. It provides a description of the research setting, the study design, the population and sample, the procedures used to collect data. Finally the permissions and ethical considerations relating to the study are outlined.

#### 3.2 Research Setting

This study was conducted within the Cape Metropolitan area. This area has a population size of approximately 3.7 million on a 2500km<sup>2</sup> landscape inhabited by different ethnic groups. A large part of the less-affluent population lives on a flat area of land called the Cape Flats. Several not-for-profit organisations exist in the Cape Flats rendering services and support to survivors of a spinal cord injury after discharge back into their respective communities.

#### 3.3 Research Design

This was a descriptive and exploratory study that utilised a qualitative approach as the researcher wants to explore and then explain the phenomena under investigation (Mouton, 1996). In this study the researcher aimed to explore the experiences individuals with a TSCI have with physical activity participation. One of the major distinguishing characteristics of qualitative research is the fact that the researcher attempts to understand people in terms of their own definition of their world (De Vos, 2002). This approach therefore gives the

researcher an opportunity to describe the individuals' experiences with physical activity participation and gives credibility to their perceptions. According to Rubin and Rubin (1995), the qualitative approach allows the researcher to share the world of others, to find out what is going on and understand why people behave the way they do. For these reasons, the descriptive-qualitative approach was considered ideal for this study in order to present the participants experiences with regards to their involvement in physical activity.

Photo-voice methodology is gaining popularity as a research approach and has been used in diverse populations (Novek, Morris-Oswald & Menec, 2012) and used in relation to health assessment and health promotion (Downey, Ireson & Scutchfield, 2009). The term photo-voice refers to a photographic technique and essentially this technique permits individuals in a community to record and reflect on their experiences in their respective communities (Wang & Redwood-Jones, 2001). This technique is further based on the idea that local people are experts in their communities and therefore knows what is needed to improve their quality of life. Furthermore, the use of the photo-voice technique was deemed appropriate for this study as this would allow the participants to depict their experiences of physical activity/exercises in their respective communities by means of photographs. Participants could therefore give a valid reflection of their experiences with regards to their involvement or lack of involvement in physical activity in their respective communities. In addition the photo-voice technique also empowers research participants and gives them the opportunity to voice their opinions both individually through taking photographs and collectively through group discussions related to their photographs (Castleden et al., 2008).

### 3.4 Population and Sampling

Creswell (2003) emphasized the importance of selecting individuals for qualitative research that would assist the researcher to understand the research problem. All types of sampling in qualitative research are considered under the umbrella term, purposeful sampling (Patton, 1990). The researcher therefore decided to approach not-for profit organizations involved with survivors of spinal cord injuries in the selected community as individuals in these organizations would maximize the opportunity of gaining rich data. This process of determining the initial sample in this manner is what is described by Coyne (1997) as the fundamental principle of purposive sampling.

The not-for profit organizations keep a registry of participants to whom they render services and support to after sustaining a TSCI in the selected community. These organizations approached individuals first to obtain their permission to invite the researcher for an information session on a specified day at the normal venue of meetings. After the initial meeting, recruitment for the study started. Leedy and Ormrod (2007) stated that 5-25 individuals for qualitative research are adequate. Although no “a priori” sample size was developed, approximately 15-20 participants were recruited to start off. The inclusion criteria for the study was all participants with a confirmed spinal cord injury; 18 year and older; residing in the Cape Metropolitan area; and who can speak, comprehend and are proficient in English, Afrikaans or Xhosa. Participants with a mental disability; those younger than 18 years of age; and those not consenting was excluded from the study.

### **3.5 Data collection methods and procedures**

Consenting participants were visited by the researcher for data collection in the environment indicated by the participants. Once the participants were recruited, information sessions were held at the venues indicated and used by the not-for-profit organizations. At the first meeting participants were given details of the project and to distribute cameras. The photo-voice methodology was explained to all the participants.

Participants were requested to take photographs that captures the theme of the study, i.e. barriers and facilitations to physical activity participation in their community. The researcher made no attempt to influence or define the themes that might emerge. This is in agreement with Wang and Redwood-Jones (2001) that argues that one of the biggest challenges of photo-voice technique is the level of guidance given to participants.

Basic training was provided to the participants and on how to take photographs, how to take photographs that respects the rights of primary and secondary participants. In addition participants were provided with information regarding their photographs can be used to tell stories. Each participant was given a disposable camera and instructions on how to use it. The researcher worked with all the participants to ensure that they were comfortable using the cameras. In addition the researcher made sure that the participants were aware that the research aimed to understand the barriers and facilitators to physical activity participation in their communities, therefore what and why they captured, and not to judge the quality of the photographs. It is recognised that photovoice can produce a large amount of data and therefore the participants were asked to take a maximum of 14 photographs. All participants were instructed to return their cameras within one week. Photographs were developed by the researcher.

After participants returned the cameras, and the photographs were developed, sessions were held with all participants individually. Typical of the photo-voice technique, each participant was asked to select five of their photographs that best present the given theme or the ones that they wanted to make sure are discussed in the focus group discussion. The researcher worked with each participant and used the abbreviated adaptation of the writing exercise as proposed by Wang, Cash and Powers (2000). The researcher asked the participants what was in the photographs, why it was taken (in relation to facilitators and barriers to physical activity participation in their community) and what the photograph meant. Narratives and captions for each photograph were therefore produced.

**Photo-voice elicited Focus group discussions:** Following the individual sessions, participants were invited to participate in one of two focus group discussions in which they were asked to elaborate on the meaning of the photographs. Participants were asked to display their photographs and narratives to the group. The photographs were used to generate a discussion around the theme of the study. The group was asked to discuss the issues that are represented across all the photographs. Although there were some general topics for investigation with possible prompts to help guide the discussion, this method allowed the exploration of themes and ideas that emerged during the discussion. The group discussions were tape-recorded and transcribed.

### **3.6 Data analysis**

Thomas (2003) stated that a wide range of literature that clearly outlines the assumptions and procedures associated with qualitative data exists. These are often associated with specific approaches such as grounded theory (Strauss & Corbin, 1990), discourse analysis (Potter &

Wetherall, 1994) and phenomenology (e.g. van Manen, 1990). Some analytic approaches are however generic and not labelled according to one of the specific traditions of qualitative research (Silverman, 2000).

According to Onwuegbuzie, Dickinson, Leech and Zoran (2009) transcript-based analysis is the most rigorous method of analysing data. *Patton (1980) states that qualitative data analysis is inductive because patterns and themes emerged from the data rather than being imposed on them.* The analysis of the focus group discussions commenced with the transcription of the information from the audio tape recordings to produce a manuscript.

The steps followed with the analysis of the data included the following (Terre Blanche & Kelly, 1999): familiarisation and immersion (the transcriptions of the information from the audio tape recordings of the focus group discussions and the narratives of the participants related to the selected photographs, was read several times to gain a sense of the whole database); introducing themes (this process was inductive and the transcripts were read through several times by the researcher with the emphasis on the emergence of ideas and themes); coding (data was marked as it relates to one or more of the themes); evaluation (during this stage the broad categories were created and the data was examined several times); interpreting the themes (categories were compared and examined for meanings and connections).

### **3.7 Trustworthiness of data**

Trustworthiness of qualitative research generally is often questioned by positivists, perhaps because their concepts of validity and reliability cannot be addressed in the same way in the



naturalistic work (Shenton, 2004). To address this, Guba (1981) proposes 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/ generalizability), dependability (in preference to reliability) and confirmability (in preference to objectivity). Credibility of the qualitative data was achieved through membership checking. This involved asking each participant to read through the transcript of the dialogue in which they participated. The emphasis was on whether the participants consider their words match what they actually intended, since articulations themselves will be accurately captured (Shenton, 2004). Also, triangulating through data source was also employed to enhance credibility of the qualitative data collection by making use of a wide variety of informants. Through triangulation, individual viewpoints and experiences could be verified against others and, ultimately, a rich picture of the attitudes, needs or behaviour of those under scrutiny was constructed based on the contributions of a range of people (Shenton, 2004). Transferability of the qualitative was enhanced through provision of sufficient contextual information about field work sites (Firestone, 1993) as well as detailed description of backgrounds of the subjects. Methods to be employed in data collection, data analysis and interpretation are properly described. In order to address dependability of the qualitative data, the research design and its implementation, the operational detail of data gathering and reflective appraisal of the thesis are reported in detail (Shenton, 2004). Confirmability/objectivity of the qualitative data was achieved through the process 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 that decisions. Also, an independent researcher was asked to read through the transcription, discuss it and compare it with researcher's transcription.

### 3.8 Ethics

Permission to conduct the study was obtained from the Senate Higher Degrees Committee and Senate Research Ethics Committee at the University of the Western Cape (UWC) (Appendix A). Further permission was sought from the not-for-profit organizations in the Cape Metropolitan area. The study was conducted according to the guidelines proposed by UWC and the Faculty of Community and Health Sciences Research Committee. The following guidelines were observed: The purpose of the study was clearly explained by the researcher to the participants and relevant authorities (Information sheet: Appendix B). Signed, written informed consent was sought from all participants (Consent form: Appendix C). Participation in the study was voluntary. The participants were informed of their rights to withdraw from the study at any time without any consequences. Participants were treated with respect and dignity. The consent forms, and information sheets was available in Afrikaans, English and Xhosa. Information obtained from participants was for the study only and was handled with confidentiality. Pseudonyms were used to protect participants' identities and when results are to be published. Information obtained from the focus group discussions was handled with confidentiality. In addition, the limits of confidentiality was discussed with each participant to enable them to make an informed decision about what material (photographs) to disclose to the group. Participants in the discussion signed a form where they undertake not to disclose any information from the focus group discussions (FG confidentiality binding: Appendix D). All tapes were destroyed once they have been transcribed and documented according to themes. All information will be kept for a minimum of five years where after it will be destroyed. Although taking photographs of objects or places presents a low risk to participants, taking photographs of other people may incur risks. Therefore before participants were given the cameras, the researcher discussed with the participants how to make safe

choices about what and who to photograph. They were also informed to obtain verbal consent from people if they wish to take a photograph with people in it. If people were photographed, their faces were obscured in the focus group discussion and in any research reports. Participants were instructed not to trespass on others' property. If participants were affected by the study and they experience any distress, the participants was informed that they will be referred to a counsellor for management through the various offices of QASA. The findings of the study will be made available to all the relevant stakeholders.

### **3.9 Summary of the chapter**

This chapter outlined the methods used to answer the stated objectives of the study. A clear description of the procedures involved in collecting the data was provided. In addition the ethics guiding the study is described. The next chapter will outline the results obtained from the thematic analysis of the focus group discussions.

## CHAPTER FOUR

### RESULTS

#### 4.1 Introduction

This chapter outlines the results of the study based on the main themes identified during the photo-voice elicited focus group discussions which attempted to answer the overall aim of the study, namely to explore and describe the experiences of community dwelling survivors of spinal cord injuries regarding physical activity participation. A description of the study sample is also provided in this chapter, i.e. from the initial number of participants recruited to the final number of participants that took part in the focus group discussions.

#### 4.2 Description of participants of photo-voice elicited focus groups discussions

Twenty (20) participants received cameras at the first meeting and 14 participants returned their cameras to allow the development of photographs. Six participants were followed up but they indicated their withdrawal from the study. Of the 14 participants, 12 participated in the focus group discussions. Two participants, not participating in the focus groups were female. Their reasons for not participating in these FGD's included health complications (bedsores) and transport related difficulties. Three participants' data were excluded based on the inclusion criteria (no SCI). They were however allowed to participate as the researcher felt it was unethical to exclude them from the discussions. The focus group discussions took place in a convenient setting for all the group members. All the participants were encouraged to fully participate in the discussions. The demographic information of the participants are summarized in Table 4.1. The mean age of the participants was 42.25 (SD= 10.79).

**Table 4.1 Demographic characteristics of participants (n=9)**

ID	Age	Gender	Level of injury	Activity Level Prior to Accident	Current level of activity	Employment status
CM	54	Male	paraplegia	Soccer/Boxing	Wheelchair basketball Wheelchair racing	Unemployed
AS	54	Male	paraplegia	All sports	Wheelchair basketball	Unemployed
MC	52	Male	paraplegia	Soccer	Road races, wheelchair basketball and tennis	Unemployed
AG	42	Male	paraplegia	Soccer	Wheelchair basketball and tennis	Unemployed
RB	43	Male	Quadraplegia	Soccer, volleyball	Wheelchair rugby	Employed
TW	31	Male	Quadraplegia	Very active, all kinds of sports	None	Unemployed
SR	23	Male	Quadraplegia	Running	None	Unemployed
TC	42	Male	Paraplegia	Soccer	Wheelchair basketball	Unemployed
AJ	28	Male	Paraplegia	Soccer	Wheelchair basketball	Unemployed

### 4.2.1 Emerging themes

Participants in the focus groups discussed various issues related to their involvement in physical activity or exercise in their community. Five themes were generated from the thematic analysis.

- Knowledge of the benefits of physical activity or exercise
- Getting to and from facilities for physical activity or exercise
- Availability of facilities
- Influence of weather
- Future plans regarding involvement in physical activity

Verbatim quotes and *the most appropriate sample photographs* are used to illustrate the themes outlined above. Therefore even if more than one participant's photograph was suitable, the most appropriate one is used in this chapter and therefore some not illustrated. For the theme related to the knowledge of the benefits of physical activity, no photographs are used to illustrate the theme, instead verbatim quotes only are used.

#### 4.2.1.1 Knowledge of the benefits of physical activity or exercise

It became clear from the focus group discussions that participants are aware of the benefits to be physically active as illustrated by the quote below:

*"... Indeed. All people with disabilities should be physically active...to stay healthy."* (AS)

*"I think it is very important because for me, I'm discovering very stiffness in my body... by not exercising."* (SR)

It also became clear that participants were aware of the associated benefits of physical activity even before their injuries as illustrated below:

*“... I was always aware of the benefits of being physically active, and also being active leads to being fit also. If you fit there’s health benefits.” (RB)*

*“I was always very active, I took part in all kinds of sports, cricket, soccer, rugby.”(SR)*

Participants also indicated that although they were very active before, their perception of their ability to be physically active or to exercise has changed somehow:

*“...I cannot do all the sports I did before, I am paralysed now. But I can still do the things I want to, it’s just that I am in a wheelchair, but nothing is impossible when you are in a wheelchair.” (AJ)*

*“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)*

#### **4.2.1.2 Getting to and from facilities for physical activity/exercise.**

Three sub-themes were identified under this major theme. These sub-themes were transportation, getting around on roads and getting in and out of the house. These are described below:

## a) Transportation

Participants highlighted that although some facilities are available in their communities for individuals with spinal cord injuries to participate in physical activity and/or exercise, transportation to and from these facilities are problematic.

The three main areas elicited from the discussion, centered around minibus taxis, busses and train stations.

### Mini-bus taxis

Although mini-bus taxis are easily available in the selected community, concerns regarding the use of these mini-bus taxis for individuals with spinal cord injuries were highlighted. Participants alerted to the fact that there is an additional cost associated with the use of mini-bus taxis as illustrated with the quote below.

*“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)*

To illustrate this concept, a participant photographed the inside of a mini-bus taxi illustrating that a seat will be taken away to make space for a wheelchair (Figure 4.1).





**Figure 4.1 Photo of a mini-bus taxi taken by male age 54 (CM)**

Participants also highlighted that entering a taxi was not easy for an individual with a spinal cord injury and that they often need help from someone to get into the taxi as illustrated below:

*“if I were to get into a taxi then I need to get somebody to lift me out of my wheelchair and put me into the taxi. (CM)*

To illustrate the narrow space that must be negotiated by an individual, and the need for assistance, a participant photographed the space available in the mini-bus taxi (Figure 4.2).



**Figure 4.2 Photo of a minibus taxi taken by male age 54 (CM)**

## Busses

Busses as means of public transport, to get to and from facilities for exercises are also available in the selected community. Participants however highlighted that these busses are not accessible when in wheelchair.

*“The bus is too high, the platform of the bus is too high from the pavement.”*

(AS)

It also became clear from the participants that wheelchair friendly busses only travels in the more affluent urban areas, as illustrated by quote below:

*“And in Sea point there’s no people, since I’ve been moving on these busses... I travel this bus 5 or 6 times just to make sure, there’s no disabled people in this bus, because the bus is driving where the white people is, and the white people, everybody got his own car.” (AG)*

This sentiment was illustrated by a photograph taken by participant of the gap between the bus entrance (with step) and the pavement (Figure 4.3).



**Figure 4.3 Photo of bus taken by male age 54 (AS)**

### **Train stations**

In addition to mini-bus taxis and busses, the other means community members have to reach facilities are with trains. Although this is a possibility, the difficulties experienced with transport with trains are very clear from the quote below.

*“if you want to get on to the platform at a station, then you need to ask someone for assistance “ (AJ)*

A photograph taken by a participant illustrate the stairs that must be navigated to get to the platform (Figure 4.4).



**Figure 4.4 Photo of stairs at the train station taken by male age 28 (AJ)**

#### **b) Getting around on roads**

Some participants do not have to make use of public transport because of their

proximity to the facilities offering physical activity or exercise. In addition to saving money they also highlighted that it is beneficial to their health to get to facilities with their wheelchairs. Participants however highlighted that despite the benefits associated with using their wheelchairs to get to the sports facilities or centres, some obstacles have to be overcome too, as illustrated with the quote below :

*“on this pedestrian crossing are no ramps built so wheelchair users cannot cross the road from the left or right side of the road.” (MC)*

The photograph taken by the participant illustrate this sentiment (Figure 4.5).



**Figure 4.5** Photo of a pedestrian crossing with no ramps, taken by male age 52 (MC)

Further on the conditions of the roads in their community, a participant had this to say:

*“The road is so steep that if you don’t have control, you can get injured in your own wheelchair.”*

### **c) Getting in and out of the house**

Individuals with spinal cord injuries need extended time to prepare themselves for the day ahead and need space to move around in a wheelchair. Most participants live in council houses (low cost housing) which has limited space to move around with a wheelchair. It is also very difficult to move around the house. Participants highlighted that trying to get ready for physical activity or even getting to the facility on time for exercise has its difficulties due to space in around their houses. This is illustrated by the quote below.

*“The problem is the stairs in my house. I can’t go up the stairs on my own or down the stairs on my own” (AS)*

This photograph taken by the participant illustrated the stairs in his house that needs to be navigated every morning and evening (Figure 4.6).



**Figure 4.6 Photo of stairs taken by male age 54 (AS)**

A participant staying at a centre for individuals with disabilities highlighted the problem of the steep and unsafe ramp in the center. They highlighted that it is difficult when going up the incline especially for those who do not have full function of their hands. This was illustrated by the quote below:

*“but in the place is not so accessible for wheelchairs..... there is a ramp for someone who pushes his/her wheelchair, but it is very difficult too push up the ramp.” (MC)*



The participant tried to capture the danger of this ramp in the centre for individuals with disabilities in this photograph ( Figure 4.7).



**Figure 4.7 Photo of a ramp taken at a centre for individuals with disabilities by male age 52 (MC)**

Further to the point of experiencing difficulties in getting ready to leave the house to attend sessions at the sports centre, participants highlighted the difficulty of getting ready in their small houses. This was illustrated by the quote below :

*“It almost takes me 30 minutes just to get into the chair and downstairs” (AS)*

#### **4.2.1.3 Availability of facilities**

Despite the challenges experienced by participants, they reported that some facilities are available for individuals with spinal cord injuries to engage in physical activity or exercise. Participants highlighted the positive influence these facilities have for their physical activity or exercise participation. This is illustrated by the quote below:

*“ I stay about 2km away from the facility “ (AJ)*

*“ Some of us live 2 to 3km from the closest facility” (TC)*

In addition to the availability of the facility participants commented on the accessibility of these facilities:

*“the facility is wheelchair accessible, its disabled-friendly.... I do some of my sports inside.” (CM)*

The photograph( Figure 4.8) illustrates the entrance to the facility and its accessibility for individuals with wheelchairs.



**Figure 4.8 Photo of a sports facility taken by male 42 (AG)**

In addition to providing opportunities for physical activities or sports, the facilities also offer some recreational activities for individuals with disabilities such as pool tables.

*“ the pool tables are accessible and we have space to move around the table with our wheelchairs (TC)*

This photograph taken by a participant to illustrate that it is suitable to use for individuals in wheelchairs( Figure 4.9 ).



**Figure 4.9 Photo suitable pool boards taken by male age 42 (TC)**

Besides the facility that is purposely built for individuals with disabilities to engage in physical activity and exercise, participants reported that other potential buildings are available in their community.

*“ it is not a fitness centre or so, but is an area that can be used.... Because it is big enough to play a game of dart or dominos. (RB)*

Despite the fact that there is potential for use of some facilities, other obstacles were highlighted:

*“But we cannot get into it... the owners refuse to build a ramp or let someone build one .” (RB)*

A participant photographed the front of a potential site for physical activity or exercise illustrating the lack of a ramp to enable wheelchair users access to it( Figure 4.10).



**Figure 4.10** Photo of a potential facility taken by male age 43 (RB)

#### **4.2.1.4 Weather**

Besides the man-made obstacles that prevents individuals with spinal cord injuries to part take in physical activity or exercise, nature can also influence their ability to take part in physical activity or exercise. Participants highlighted that the weather plays a huge part in their efforts to partaking in physical activity or exercise.

Participants highlighted that staying in an area where strong winds are a factor, is something to take into consideration for them. As illustrated below:

*“ as a disabled person you have to check the weather first, it is very difficult to travel with a wheelchair to the facility against a 50km wind and you live 3km away, you tired when you get here.” (AJ)*

*“ ....many times we have to study the weather, if you are wheeling with or against the wind.” (AS)*

In addition to the wind, rain is another factor that must be considered by individuals when attempting to get to facilities. This is illustrated by the quote below:

*“ when it is raining you travel to the facility you wet, how do you train when you wet? “ (CM)*

Besides the effect rain has on the individuals, the impact of rain and the consequences for the wheelchair was also mentioned:

*“ Rainy days you have to consider control of your wheelchair...is my control going to get wet... to maintain a electric wheelchair can be very expensive.” (TW)*

#### 4.2.1.5 Future plans

Although the government built facilities in the community to promote physical activity or exercise amongst individuals with disabilities, the participants are of the opinion that government can still improve some of the issues or challenges raised by them. Participants mostly highlighted the accessibility of public transport that is a problem. This is illustrated by the quote below.

*“ I would like the government to look at an integrated transport system that works within the townships.” (TC)*

*“ ... they made us a promise, when My Citi come out, it will be wheelchair accessible....” (TW)*

*“Now they bring out the busses, the busses can only transport one person.”*

Furthermore a participant added that people with disabilities should take responsibility for themselves and do more research to help the government with some legislations regarding disability. The quote illustrated the participants sentiment:

*“ ...we have to take responsibility to keep the government on its toes to make sure they implement the legislation that is there.” (AG)*

#### 4.3 Summary of the chapter

This chapter presented the findings of the thematic analysis of the focus group discussions. The themes identified were outlined and is complimented and illustrated



with the verbatim quotes and photographs. These findings will be discussed in the next chapter.

## CHAPTER 5

### DISCUSSION

#### 5.1 Introduction

The primary objective of this study was to explore the experiences of physical activity of community dwelling survivors of spinal cord injuries. Data for the study was collected by means of photo elicited focus group discussions. This chapter discuss the findings of the thematic analysis of the focus group discussions and compares it to the salient literature in the area.

#### 5.2 Use of photo-voice technique for this study

Researchers have stated that photo-voice is increasingly becoming more popular as a participating research methodology (Novek, Morris-Oswald & Menec, 2012; Catalan & Tinkler, 2010). This methodology has been used in a diverse set of populations (Castleden, Garvin & Huu-ay-aht First Nation, 2008; Schwartz et al; 2007; Killion & Wang, 2000)but few have described the use of this methodology for individuals surviving a spinal cord injury. One of the main reasons why this methodology was found appealing for this particular study was the idea that local people are experts in their communities as described by Novek et al. (2012). Furthermore, as described by Castleden et al. (2008) the photo-voice technique gives individuals a way of “voicing” their opinions through taking photographs (individually) and through participating in focus group discussions, discussing the photographs (collectively). Bell and Menec

(2012) also stated that photographs allow participants to portray their lived experiences and it also help to shape the discussions in a focus group.

After each participant selected five of their photographs, and developed captions and narratives, the issues were discussed in two focus groups. The thematic analysis that followed resulted in the generation of five themes. The findings will be discussed under the headings, knowledge of the benefits of physical activity; barriers and facilitators of physical activity participation for survivors of a spinal cord injury; and lastly the participants views on their future plans regarding physical activity participation.

### **5.3 Discussion of emerging themes**

The ICF, put forward by the World Health Organisation, attempts to “encompass all aspects of human health and some health-relevant components of well-being and describes them in terms of health domains and health-related domains” (WHO, 2001b, p. 8). These health-related domains are placed into two broad categories namely: (a) functioning and disability and (b) contextual factors. Functioning and disability includes two components: (a) body function and structure and (b) activities and participation. Contextual factors include two components as well: (a) environmental factors and (b) personal factors (WHO, 2001a).

Environmental factors denote the physical, attitudinal, and social environment in which a individual lives. This study utilized the ICF’s environmental factors to explore the influence

of the environment on a survivor of a spinal cord injury's ability to function and reintegrate into their communities. The environmental factors are conceptualized in the five domains: (a) products and technology, (b) natural environment and human-made changes to environment, (c) support and relationships, (d) attitudes, and (e) services, systems and policies.

#### **5.4 Knowledge of benefits of physical activity and exercise**

As stated in the ICF, the health-relevant components of well-being includes contextual factors, both environmental and personal factors. The knowledge that an individual has with regards to physical activity and specifically the benefits thereof, can be seen as personal factors.

Scientific evidence shows that physical activity can be used to promote health and to treat physical and mental illness (WHO 2010; Fagard & Cornelissen, 2007). Kehn and Kroll; (2009) also reported physical activity as a key public health indicator in people with limitations, such as spinal cord injuries, but yet research has shown that individuals with spinal cord injuries are less likely to be physically active compared to able bodied individuals. These authors further reported that knowledge of physical activity or exercise may enhance participation after spinal cord injury and is crucial with regards to health professionals to cater for their needs. The majority of participants in this study showed a keen awareness of the benefits associated with physical activity. Various benefits of physical activity for individuals surviving a spinal cord injury was offered by the participants in this study, such as: "... *All people with disabilities should be physically active... to stay healthy*". This is similar to the findings of Kehn and Kroll (2009) that individuals with spinal cord injuries positive

attitude towards exercise was linked to their knowledge of the benefits of being physically active. Wu and Williams (2000) also reported that participants in their study was aware of the benefits of maintaining a level of functioning. Further in agreement with the current study, Tasiemski, et al. (2004 ) reported reasons for being physically active as a way to maintain good health, improve their upper body strength and getting out of the house and meeting people.

The minority of the participants not active currently, still displayed a keen awareness of the benefits of being physically active, “*I think it is very important because for me, I’m discovering very stiffness in my body... by not exercising*”. This is very positive as other studies highlighted the opposite in that survivors of spinal cord injury not currently active perceived being active as unrealistic, unattainable or simply too demanding (Ken & Kroll, 2009). Wu and Williams (2000) also described that non-active participants in their study found it frustrating to exercise with their physical impairments. It must be noted that those not currently active in this study were both quadriplegics, relatively young and very active prior to their injuries. In the light of their awareness of the benefits of physical activity, Wu and Williams (2000) recommendation for health professionals to provide education with regards to sports and leisure activities, should be considered.

As stated before all the participants of this study were fully aware of the benefits of physical activity. Even though participants had some knowledge of the benefits of physical activity no mention was made of promotion or events to make other individuals with spinal cord injuries aware of the benefits of physical activity or

exercise. Scelza, et al. (2005) also reported that less than half of the participants in their study indicated that their physician recommended exercise to them. These findings highlighted the real need of concerted efforts by healthcare professionals to promote engagement of physical activity to individuals who survived a spinal cord injury.

### **5.5 Barriers and Facilitators to physical activity and exercise**

Despite the large body of evidence with regards to the benefits of physical activity various factors exist that influences individual participation. Robertson, et al. (2011) reported that for both the general population and individuals with spinal cord injuries, barriers to exercise may be internal or external. In the study of Levins et al, (2004) they reported that numerous investigators examined barriers to physical activity in the general public, but the degree to which these barriers were relevant to individuals with spinal cord injuries was in question.

Most of the challenges experienced by participants in the present study to participation in physical activity or exercise were related to the domain “products and technology” of the ICF. These challenges are related to the physical environment and land development was the most problematic area, and several of the photographs illustrated these barriers encountered in the exterior environment such as sidewalks, ramps and curbs. Despite their willingness and motivation to use their wheelchairs to get to the facilities offering physical activity opportunities, participants highlighted that the roads were not suitable for wheelchair users (no ramps at pedestrian crossings, high curbs) and they also highlighted the poor conditions of their roads in their community (pot holes). Living in a less affluent area

most participants lives in counsel houses (low cost housing) which they identified as very small. Due to their disability individuals with spinal cord injuries need time and space to prepare themselves before they leave their houses. The highlighted the difficulty of being able to move around their houses as a barrier. They highlighted the fact of needing assistance to leave their homes. All these issues raised above are consistent with that of Scelza et al (2005) and highlights the fact that attention must be given to the socio-environmental resources too when physical activity promotion are done for individuals with disabilities.

Although participants recognized that facilities were available to them, accessibility to the facility was of some concern to them. Services and systems related to transport was also a domain that posed a huge challenge to the participants. Transportation to and from the facility was of great concern and expressed by many of the participants. Living in a less affluent area the majority of the participants used public transport such as mini-bus taxis, busses and trains to get to a facility and this means of transportation was not accessible for wheelchair users. *"The bus is too high...."* and *".... I need to get somebody to lift me out of my wheelchair and put me into the taxi."* In addition to the physical barriers posed by busses and taxis participants reported that public transport, i.e busses that was accessible and available to them, was too little for the amount of wheelchair users in their community. Furthermore these busses are being used in the more affluent areas which in their opinion are being underused by wheelchair users. Participants also highlighted that not having accessible public transport for wheelchair users, they have to resort to other means of transport such as private taxi's which can come at a financial cost to them.

The findings highlighted above are very similar to that of Rimmer et al (2004) that reported lower levels of physical activity among African-American women, living in the inner-city of Chicago, due to the high cost and or lack of transportation in the area. These similarities highlighted the added “barrier” of poverty for individuals living in less-affluent areas such as the current study. Literature highlights that for individuals who are more affluent such as those reported by Scelza et al. (2005) transportation is not seen as a barrier to physical activity.

The findings above clearly demonstrates how some issues regarding physical activity participation for community dwelling survivors of spinal cord injuries are beyond their control. Issues particularly associated with poverty and the social environment are clearly highlighted as an area that must be investigated further. It must be recognized however that the socio-environmental barriers highlighted regarding accessibility are not unique to the area of exercise or physical activity but it is related to health generally too (Kehn& Kroll, 2009). Researchers also highlighted that the removal of socio-environmental barriers could prove to be one of the most effective ways to facilitate and motivate participation in physical activity or exercise for individuals with a spinal cord injury (Kehn& Kroll, 2009).

Participants in the current study highlighted that they found the facility in the community as suitable for individuals with spinal cord injuries and that is freely



accessible to them. Participants highlighted that they could practice various sporting types/activities such as wheelchair basketball and suitable pool tables. This is encouraging to note as literature highlighted that despite the availability of facilities, some individuals do not make use of it as full utilisation of these facilities depends on the attitudes of individuals (Levins et al; 2011). Unlike the research done by others (Levins et al; 2014; Robertsonetal; 2011) participants in the current study did not verbalize internal barriers to participation in physical activity.

In our study the participants identified the improvement of the facilities in their communities but accessibility to and from facilities was a problem but that they still made an effort to be physically active. This corresponds with the study done by Levins, et al. (2004) in which they recognized that the accessibility of facilities was improving but participants would remark on the inaccessibility of many facilities in their communities. Further to this, Kehn and Kroll (2009) reported that participants that exercised regularly had accessible community based facilities or good home equipment, where the participants that did not exercise often regarded the lack of such accessible facilities or equipment as a barrier. Living in a less affluent area participants make use of the community facility for physical activity or any form of exercise and the range of physical activity is very limited to the participants themselves, because other equipment or facilities come at a financial cost.

This study included participants with different levels of injury and the majority of them still attempted to stay physically active irrespective of the external barriers or internal barriers. This is slightly different from what is reported by Scelza et al. (2005)

where individuals indicated that their lack of exercise was because of their injury levels. These authors further indicated that individuals with tetraplegia indicated that it was too difficult to exercise. All the participants in the study participated in able-bodied sports (soccer, athletics, rugby) before their injuries and the majority still participates in physical activity after their injury even though it is not the same sport they participated in before the injury. This is similar to what Kehn and Kroll (2009) reported in their study that exercisers acknowledged that their exercise routines and strategies had changed after injury but the reasons for staying physically active had not.

Factors related to the natural environment received attention too, although not captured by photographs, this was captured in the focus group discussions. The most frequent challenge experienced was related to the climate/weather in particular the wind and rain. Participants highlighted that in addition to the difficulty the experience to get to and from facilities they also had to take the weather into account. Individuals with spinal cord injuries are more susceptible to secondary conditions when not exercising compared to able bodied people. Van der berg-Emon et al. (2008) reported that individuals with spinal cord injuries are more at risk to develop a hypoactive life style compared to able-bodied individuals, which could lead to secondary condition. Therefore despite their knowledge of leading an active lifestyle, they need to take into consideration the consequences of being exposed to severe weather conditions for their health too. Living in the community where people depend mostly on public transport and where individuals with spinal cord injuries are more at risk to secondary conditions than able-bodied individuals, they find it difficult to being physically active if the weather conditions are not favourable to them. The need for good transport options are thus even more important to be considered.

## 5.6 Future plans

Issues related to services, systems and policies were also addressed in this study. With regards to the future plans for involvement in physical activity or sports, participants mostly highlighted that public transport needed to be improved. This is similar to what is reported by Scelza et al. (2005) that highlighted that accessible transportation was needed for participants with spinal cord injuries. What became evident in the group discussions was that participants were aware that they also have a role to play when issues such as improvement facilities and improving accessibility of facilities are concerned. They were of the opinion that government should involve them as individuals with disabilities when they plan the infrastructure in their community for people with spinal cord injuries. Kehn and Kroll (2009) reported that individuals with spinal cord injuries needed to develop a sense of autonomy and competence, which is essential for a process of internalization and intergration of health behaviors ( i.e exercise). Kalpakjian, et al. ( 2005) had a similar report that the identification of barriers to exercise among individuals with spinal cord injuries should be the first step in reducing such barriers to facilitate participation in exercise and improve a healthy outcome.

Roberton et al. (2011) reported that future research should address the relationship between internal barriers and external barriers in individuals with spinal cord injuries. Wu and Williams (2000) also reported that future studies should examine individuals with spinal cord injuries who are non-active post-injury to identify the difficulties and reasons why they do not part take in sport and leisure activities and how they can be encouraged to participate in physical activity or sport. In a study done by Tasiemski, Gardner, Blaikley; (2004) participants not living in the city indicated that improved

facilities and access are needed at local level. In comparison to this study participants highlighted the fact that facilities for physical activity are being built in their community but they believe that government could improve the external themes discussed, the main focus on getting to a facility and also leaving it.

### **5.7 Summary of the chapter**

This chapter discussed the findings of the group discussions and compared it with the salient literature in the field. The next chapter provides a summary and conclusion of the study.

## CHAPTER SIX

### SUMMARY, CONCLUSION AND RECOMMENDATIONS

#### 6.1 Introduction

In this chapter a brief summary of the study is provided, conclusion and the recommendations arising from the study are proposed. This chapter ends with a presentation of the study's limitations.

#### 6.2 Summary

The overall aim of this study was to explore and describe the experiences of community dwelling survivors of spinal cord injuries regarding their involvement in physical activity or exercise in their respective communities. This study specifically explored the external barriers and facilitators in their community that influenced physical activity among individuals with spinal cord injuries.

The study was carried out on the basis that there is a need for physical activity among individuals with spinal cord injuries and especially among community dwelling survivors of spinal cord injuries in the Cape Metropolitan Area. Data for the study was collected by means of photo-voice elicited focus group discussions. Participants capture the themes of the study by means of photographs taken in their respective communities and focus group discussions followed.

The findings of this study was that most of the participants were aware of the importance of physical activity and the majority was 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, which was highlighted by emerging themes through a photo-voice technique.

### **6.3 Conclusion**

Taken as a whole the photo-voice focus groups that the participants formed, highlighted the need for the external factors (barriers and facilitators) in their community to improve so it could be easier for them to perform physical activity as individuals with spinal cord injuries. Although most of the participants were physically active before their injury and also after their injury they confirmed the need for physical activity or exercise for individuals with spinal cord injuries.

Although the results show that participants had difficulty with external factors that influenced their attitudes towards physical activity, they still knew the importance of it and tried to participate in physical activity or exercise regularly.

### **6.4 Recommendations**

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

- Government to provide suitable facilities for people with spinal cord injuries to participate in physical activity or exercise in their respective communities.
- Provision of suitable public transport options for people with spinal cord injuries in all communities.
- Improvement of roads, pavements, etc. in communities to remove inaccessible roads as a barrier for wheelchair use.
- Improvements of government-funded houses for people with spinal cord injuries to improve accessibility in and around their homes.

- Forum in which people with spinal cord injuries can participate to “voice” their concerns and become involved in future research.
- Future research involving a bigger sample size and a more diverse sample.

### **6.5 Limitations of the study**

The findings of this study must be considered in the light of the following limitations:

- Being a qualitative study, the sample size was small. Despite this, the researcher could collect in-depth information from the participants.
- Although the participants decided and agreed to conduct the focus groups in English, some of the participants might not have felt comfortable expressing themselves in that language.

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OFFICE OF THE DEAN  
DEPARTMENT OF RESEARCH DEVELOPMENT

12 June 2014

**To Whom It May Concern**

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by:  
Mr B Martin (Physiotherapy)

Research Project: Physical activity after spinal cord injury:  
exploring experiences in the Cape  
Metropolitan area.

Registration no: 14/5/23

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*

## APPENDIX B

# UNIVERSITY OF THE WESTERN CAPE



Private Bag X 17, Bellville 7535, South Africa  
Tel: 0218625716, Fax: 0218625716  
E-mail: [brentmphysio@gmail.com](mailto:brentmphysio@gmail.com)

## INFORMATION SHEET

**Project Title: Physical Activity after Spinal Cord Injury: Exploring experiences in the Cape Metropolitan area.**

### **What is this study about?**

This is a research project being conducted by **Brent Martin** at the University of the Western Cape. We are inviting you to participate in this research project because you are an individual who has sustained a traumatic spinal cord injury. The purpose of this research project is to inform individuals with spinal cord injury about the benefits of physical activity or exercise as well as exploring the barriers to perform physical activity or exercise.

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

You will be asked to share your experiences in physical activity and if you experienced any barriers to perform any physical activity. This study will be conducted in the Cape Metropolitan area. You as an individual with a spinal cord injury will also be asked about medical history e.g. (pressure ulcers, diabetes, high blood pressure etc.). An in-depth, semi-structured interview and observations and photo-voice will be used. Some questions that will be asked will focus on your experiences in physical activity as well as your experiences in barriers to perform any physical activity. As well as your future plans to engage in physical activity.

### **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, all data collected from this study will be stored on a computer that only the researcher/s has access to. This information can only be accessed through a secure password that only the researcher/s knows. All data or information collected from you as an individual will remain confidential and your name or any personal information will not be included in this study. If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning child abuse or neglect or potential harm to you or others.

### **What are the risks of this research?**

***There are no known risks associated with participating in this research project.***

### **What are the benefits of this research?**

The benefits to you include *information of the benefits of physical activity and information of the barriers that causes a lack of physical activity in your area.*

This research is not designed to help you personally, but the results may help the investigator learn more about the barriers that causes a lack of physical activity in your area. We hope that, in the future, other people might benefit from this study through improved understanding of the benefits of physical activity and the barriers that causes the lack of physical activity in the Cape Metropolitan area.

### **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?**

#### **What if I have questions?**

This research is being conducted by **Brent Martin** at the University of the Western Cape. If you have any questions about the research study itself, please contact **Brent Martin** at 0218625716, [brentmphysio@gmail.com](mailto:brentmphysio@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 A. Rhoda  
Department of Physiotherapy  
U.W.C  
e-mail: [arhoda@uwc.ac.za](mailto:arhoda@uwc.ac.za)

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  
UNIVERSITY OF THE WESTERN CAPE  
INFORMATION SHEET TEMPLATE  
ADDITIONAL GUIDANCE FOR SPECIFIC ISSUES**

**Informed Consent**

Informed consent is a process, not just a form. Information must be presented to enable persons to voluntarily decide whether or not to participate as a research subject. Therefore, informed consent language and its documentation must be written in language that is understandable to the people being asked to participate.

**Research Involving Minors**

For research involving individuals under the age of 18, include a Parental Permission Form to ask parents for consent to the participation of their child and an Assent Form to ask the minors if they agree to participate in the research, depending on whether the children are capable of assenting. The Parental Permission form should contain all of the elements of the sample consent form. However, the parental permission form should be written in language appropriate for parents granting permission for their child's involvement rather than as though they themselves will be participating (e.g. we are inviting your child to participate the risks to your child's participation include). When determining whether the children are capable of assenting, take into account the ages, maturity, and psychological state of the children involved. Assent forms should be written in age-appropriate language.

**Research Involving Individuals with Impaired Decision-making Capacity**

Using the Informed Consent Form Template, prepare a consent form to ask the research subject's authorized representative for consent to the participation of the research subject. Prepare an assent form to ask the research subjects if they agree to participate in the research, depending on whether the subjects are capable of assenting. When determining whether the subjects are capable of assenting, take into account the decision-making capacity of the research subjects.

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**SUGGESTED WORDING**

Instructions: You should cut and paste these paragraphs, where applicable, into the appropriate area of the Informed Consent Form. However, the suggested wording below should be modified appropriately for the specifics of your study.

**Audio taping/Videotaping/Photographs/Digital Recordings**

This research project involves making [***audiotapes/videotapes/photographs***] of you. Tapes are made so it can be played back to you as a participant to make sure the interview is being done accurately .



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



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## APPENDIX C

# UNIVERSITY OF THE WESTERN CAPE



Private Bag X 17, Bellville 7535, South Africa  
*Tel: +27 21-9592542, Fax: 27 21-9591217*  
E-mail: [jphillips@uwc.ac.za](mailto:jphillips@uwc.ac.za)

### CONSENT FORM

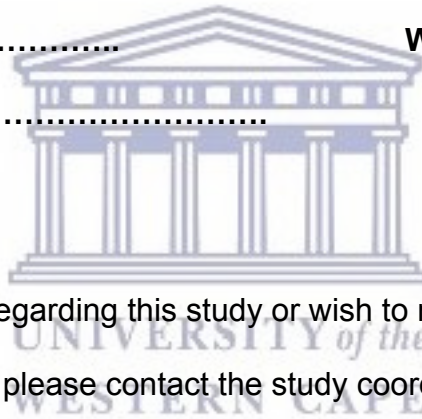
**Title of Research Project:** Physical Activity after Spinal Cord injury: Exploring experiences in the Cape Metropolitan area.

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.....



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: Prof Julie Phillips**

**University of the Western Cape**

**Private Bag X17, Belville 7535**

**Telephone: (021)959-2542**

**Cell: +27829921549**

**Fax: (021)959-1217**

**Email: [jphillips@uwc.ac.za](mailto:jphillips@uwc.ac.za)**

## APPENDIX D

# UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-9592543 , Fax: 27 21-9591217

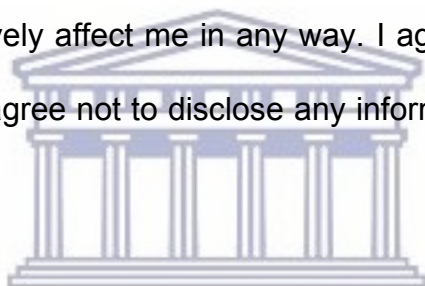
*e-mail: brentmphysio@gmail.com*

### **FOCUS GROUP CONFIDENTIALITY BINDING FORM**



**Title of Research Project:** Physical Activity after Spinal Cord injury: Exploring experiences in the Cape Metropolitan area.

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. I agree to be audio-taped during my participation in the study. I also agree not to disclose any information that was discussed during the group discussion.



**Participant's name**..... UNIVERSITY of the

**Participant's signature**..... WESTERN CAPE

**Witness's name**.....

**Witness's signature**.....

**Date**.....