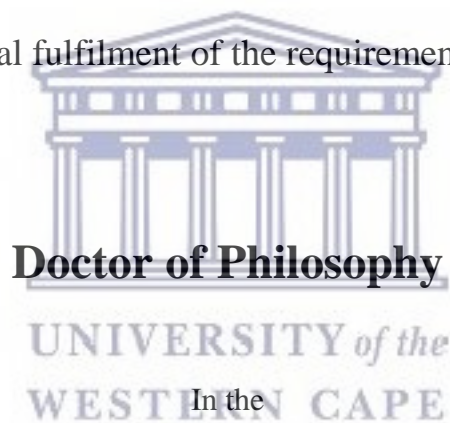


**Behavioural and protective factors contributing to the risk and
vulnerability to HIV/AIDS among individuals with spinal cord
injuries in South Africa**

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Thesis submitted in partial fulfilment of the requirements for the degree of



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At the

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SUPERVISOR

Professor JS Phillips

KEYWORDS

Traumatic Spinal cord injury

Sexual Risk behaviours

Risk and vulnerability to HIV/AIDS

Socio-cultural context

HIV/AIDS

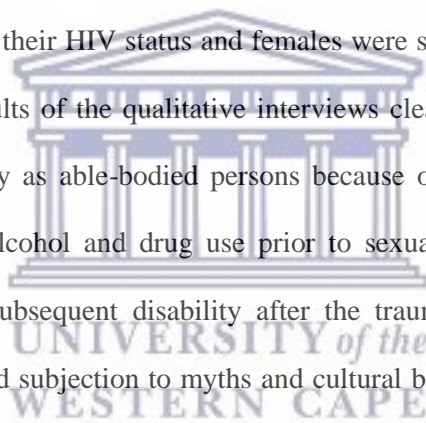


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ABSTRACT

HIV/AIDS has made a huge impact on human development and sexual reproductive habits in this century in the world and especially in sub-Saharan Africa. It has only recently been acknowledged that HIV/AIDS has an equal if not greater effect on or threat to people with disabilities. Survivors of traumatic spinal cord injury (TSCI) with resultant disability are incorrectly believed to be sexually inactive, unlikely to use drugs or alcohol and at less risk of violence or rape than their non-disabled peers. This group can thus be described as economically, educationally and socially disadvantaged, which in itself, suggest that they are a high-risk group for HIV infection. The overall aim of this study is to examine the factors that could contribute to the risk and vulnerability to HIV/AIDS among individuals with spinal cord injuries in South Africa. The specific objectives of the study are to assess the behavioral and protective factors that could contribute to risk and vulnerability to HIV infection among individuals and spinal cord injuries; and to explore the socio-cultural issues that might increase individuals with spinal cord injuries' vulnerability to HIV/AIDS. The design of this study was a mixed methods design, particularly the sequential explanatory strategy was used will used in this study. The study was conducted in four (4) conveniently selected provinces (highest prevalence of SCI). The Quad-Para Association of South Africa's (QASA) provincial databases was used to invite individuals with SCI to participate in the study. Data for quantitative part of the study was collected by means of self-administered questionnaires. The questionnaire consisted of various sections requesting for information on: Demographics; HIV-Knowledge (HIV- KQ-18); Sexual behaviours; Sexual communication and negotiation skills; Self-efficacy to refuse sex. Separate binary logistics analysis was done to assess which of the selected factors are associated with risky sexual behaviour. The forced entry method approach was used to determine which of these factors have the greatest productive power to predict sexual risk behaviour. No "a priori" sample size was developed for the qualitative part, but participants were recruited until saturation has been reached of all the categories. Consenting participants were visited by the researcher for data collection in the environment indicated by the participant. Permission to conduct the study was obtained from the Research Ethics Committee at the University of the Western Cape (UWC). The study was conducted according to ethical practices pertaining to the study of human

subjects as specified by the UWC and Faculty of Community and Health Sciences Research Ethics Committee of the UWC. Two hundred-and-forty-two (242) individuals participated in the quantitative study. The findings from this quantitative study highlight the following: About three quarters 77.9% of the study sample reported being sexually active at the time of the survey. A further 47.9% of the sample indicated condom use at last sexual intercourse. Early sexual debut was reported by 13.6% of the sample and 44.6% multiple sexual partners after sustaining a TSCI. Male participants were about 2.63 times (OR = 2.63; 95% CI = 1.17-5.91) more likely to report lifetime multiple partners. Although self-efficacy to refuse sex was low and 46.4% of participants reported not using condoms during last sexual intercourse, participants who have greater self-efficacy to refuse sex were .91 times more likely to use condoms (OR = .91; 95% CI = .85-.97). Participants reported to having had peer education regarding HIV, had significant higher HIV knowledge scores than those not receiving peer education. Overall only 24.8% of participants knew their HIV status and females were significantly more likely to know their status than males. The results of the qualitative interviews clearly showed that individuals are exposed to risk in the same way as able-bodied persons because of risk-taking behaviour such as inconsistent condom use, and alcohol and drug use prior to sexual intercourse. In addition, their vulnerability because of their subsequent disability after the traumatic spinal cord injury, posed additional risk such as abuse, and subjection to myths and cultural beliefs. It is clear that individuals with a traumatic spinal cord injury is vulnerable to the risks of HIV infection. In addition, there are cultural issues that increase the vulnerability of individuals with a TSCI to HIV in South Africa. Concerted efforts should thus be made to protect this vulnerable group of the population by means of empowerment, improving HIV-related knowledge, addressing negative attitudes from healthcare professionals and including people with disabilities in HIV prevention education programmes. In conclusion, it is recommended that in the era of the HIV/AIDS pandemic, that comprehensive team-based research be undertaken to investigate the complexity of sexual health and decision-making among people with disabilities and those surviving a traumatic spinal cord injury.



DECLARATION

I, the undersigned, hereby declare that the work contained in this thesis is my own work, that it has not previously in its entirety, or part of it submitted for any degree for examination at any other university, and that all sources I have used or quoted have been indicated and acknowledged by means of complete references.



Jacobus Lloyd



Date 30 November 2018

Witness:



Prof JS Phillips (Supervisor)

DEDICATION

In loving memory of my late father and mother "Koos en Marietjie" may your souls rest in eternal peace



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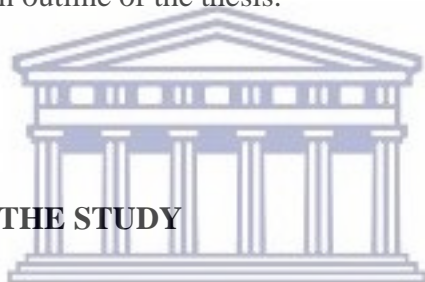
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CHAPTER ONE

INTRODUCTION

1.1. INTRODUCTION

In this chapter the rationale of the study highlights the importance of examining the behavioral factors contributing to the risk and vulnerability to HIV/AIDS among individuals with Traumatic Spinal Cord Injury (TSCI) in South Africa. The threat of HIV/AIDS for people with disabilities, and the perception that individuals with a spinal cord injury are seen as “asexual” are highlighted. The overall aim and the specific objectives of the study are stated. The chapter also includes the definition of key terms and abbreviations used in the study. The chapter ends with an outline of the thesis.



1.2 RATIONALE FOR THE STUDY

Three decades after its discovery, the Human Immunodeficiency Virus (HIV) continues to have a severe direct and indirect impact on the world's population. Since the beginning the HIV epidemic has grown to such an extent that approximately 78 million people were reported to have been infected (UNAIDS, 2014b). The United Nations Joint Programme on HIV/AIDS (UNAIDS, 2014b) further reported that approximately 39 million people have died of illnesses related to HIV. Sub-Saharan Africa has been reported to bear the burden of the epidemic, and at the end of 2013, almost 80% (27.7 million out of the 35 million) people living with HIV resided in this region (UNAIDS, 2014a). It is therefore clear that the HIV epidemic remains an increasing challenge to public health efforts.

Global efforts have been noted to deal with the HIV epidemic, and in South Africa the government has gone to great lengths to fight HIV in an attempt to reduce infections and to provide the best treatment options available, in line with these efforts (Department of Health (DOH), 2010a; Johnson, 2012; Motsoaledi, 2014). It has been stated that the HIV epidemic in sub-Saharan Africa is largely driven by heterosexual intercourse (UNAIDS, 2010b). It is therefore clear that for prevention efforts to be successful in curbing this epidemic, all the factors that influence sexual behaviour of all people of a population should be taken into consideration.

Groce et al (2013) indicated that people with disabilities have been largely excluded from HIV prevention campaign, even though a growing body of literature (Hanass-Hancock, 2009a; Rohleder, Braathen, Swartz & Eide, 2009) points to the fact that they are at equal risk for HIV infection. It is argued that this was partly because of the notion that people with disabilities are not at risk of being infected with HIV because they are a-sexual and thus not in danger of sexual exploitation (Groce, Trasi & Yousafzai, 2006). Too often individuals with disability are not included in HIV prevention and outreach efforts, such as they are, often assume that they are not sexually active and are at low risk for HIV infection, but this has been proven to be an inaccurate assumption by the Global Survey on Disability and HIV/AIDS (Groce, 2004). According to the South African Census, 2011, the disability prevalence in South Africa is approximately 2.7%, meaning that there are about 2.9 million people living with a disability in the country, excluding children under the age of four years old, and residents of institutions.

Literature has shown evidence that the sexual lives of people living with disabilities have been ignored and stigmatized as taboo (Esmail, Darry, Walter & Knupp, 2010), and persons with a

traumatic spinal cord injury (TSCI) has not eluded this stigma. TSCI is an acquired physical disability through traumatic injury to the spinal cord (Cripps et al., 2011). Available reports on traumatic spinal cord injuries indicate that between 170 000 and 250 000 of the population worldwide suffer from a traumatic spinal cord injury annually ^[6]. Recent studies in Africa have reported incidence rates of 75.6 per million population in South Africa (Joseph et al., 2015). These authors further alluded that the survivors of traumatic spinal cord injuries in South Africa are mostly male and between the ages of 18 and 29 years old. These individuals are therefore just as vulnerable as the rest of the population to the risk of HIV/AIDS as Shisana and Simbayi (2002), at the conclusion of a national survey, commissioned by the Nelson Mandela Foundation, clearly stated that HIV/AIDS affect all the race groups in South Africa and that those between the ages of 15-24 years old were most affected.

1.3 PROBLEM STATEMENT

Persons sustaining an TSCI are often of the male gender, between 16-30 years of age and of poor socio-economic background in South Africa. Because of comprehensive rehabilitation, the expectation is that they still have the future prospects of living a long life with very few possibilities of returning to a high level of functioning, complete social integration and productive living. Survivors of TSCI with resultant disability are incorrectly believed to be sexually inactive, unlikely to use drugs or alcohol and at less risk of violence or rape than their non-disabled peers. This group can thus be described as economically, educationally and socially disadvantaged, which in itself, suggest that they are a high-risk group for HIV infection. A personal observation from the researcher, who sustained a traumatic spinal cord injury in his twenties, is the lack of sufficient sexual and reproductive health promotion and education within this group regarding HIV risk behaviours and vulnerability to HIV/AIDS. In

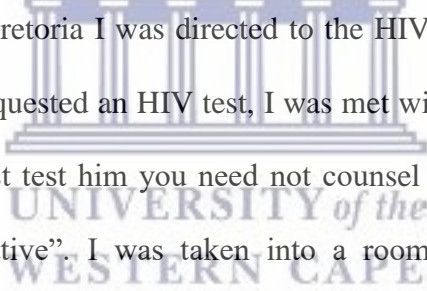
his professional capacity as an advocate for people with disabilities, it is also clear that a person with a disability, who might become HIV positive, will feel doubly disadvantaged. There is an immense lack of knowledge and research regarding the sexual risk and vulnerability of persons with TSCI in the world including South Africa. This could be associated with lack of education, information and literature directly related to the topic. This study would shed some light on why people who have sustained TSCI are at risk of being infected with HIV as a result of their disability and what factors contributes to them being vulnerable.

1.4 RESEARCHER'S POSITION IN THE CONTEXT OF THE THESIS

I am a survivor of a TSCI sustained in 1988. I subsequently became involved with other persons with TSCI's through providing peer support services at rehabilitation facilities for individuals with spinal cord injuries. During this period, I was challenged by various clients asking questions regarding sexuality and the challenges and consequences related to TSCI. In 2008, after completing my Master's Degree in Adapted Physical Activities, I started working for a disabled people's organisation called "Motivation Africa" as a Peer Support Coordinator for the African region. "Motivation Africa" was a US-based organisation and I was responsible for training people and trainers in various countries in Africa, including South Africa. Part of my responsibility was to help develop a peer support training manual and resources to use within the African context to educate persons with TSCI regarding their disability. One of the modules within this manual focused on sexuality and relationships and sexual transmitted diseases (STI's), but no clear focus on HIV specifically.

At the end of 2010 I was elected by the South African Disability Alliance (SADA) to represent the disability sector on the South African National AIDS Council (SANAC). Becoming

involved with issues related to HIV/AIDS was something new to me as I have never really thought of people with disabilities, including myself, as being vulnerable to be infected or affected. My knowledge regarding HIV/AIDS was also very limited at that stage. After being involved with the activities of SANAC for a few months, I learnt of how HIV/AIDS can affect people with disabilities. I then realised with great shock that “I AM AT RISK!” On examination of my sexual activities and lack of information regarding HIV, I was concerned and realised that I had to be tested as soon as possible. Suddenly, an upset stomach, a bladder infection and sweating at night fueled my imagination that I had symptoms of HIV. The biggest question was, however: where do I go to be tested. Despite being a confident individual, I was not only self-conscious about the test, but also the reaction of the personnel at the testing facility.



At a government hospital in Pretoria I was directed to the HIV clinic staffed by exclusively black nursing staff. When I requested an HIV test, I was met with stares from everyone and I overheard one nurse say: “Just test him you need not counsel him because he is white and disabled, so he will be negative”. I was taken into a room where, without very much explanation, my finger was pricked and blood put onto a device. I was really worried and the nursing sister asked me why I was concerned. I told her I had unprotected sex with a girl that I did not really know well a few months ago and that I was not feeling well. She apologised and explained to me that she was sorry and that she should have prepared me better for the test, but that she did not think that I was sexually active as I was in a wheelchair and that it was just a routine test.

This incident, however, made me wonder if I am the only one that needed a wake-up call. Was I the only one not being aware of the risks of being infected, just because of a lack of

information? How many other persons with a TSCI are out there that are too scared to be tested? Why are people with disabilities in general excluded from HIV/AIDS or TB programmes? With this research I would therefore like to provide evidence of the risk and vulnerability to HIV/AIDS of individuals with a TSCI, and therefore advocate for the inclusion of people with disabilities in prevention efforts.

1.5 RESEARCH QUESTION

Are individuals with a traumatic spinal cord injury vulnerable to the risks of HIV infection?

Are there any cultural issues that increase the vulnerability of individuals with a TSCI to HIV in South Africa?

1.6 OVERALL AIM OF THE STUDY

The overall aim of this study is to examine the factors that could contribute to the risk and vulnerability to HIV/AIDS among individuals with a TSCI in South Africa.

1.7 SPECIFIC OBJECTIVES OF THE STUDY

(a) To assess the behavioural factors that could contribute to risk and vulnerability to HIV infection among individuals with a TSCI.

- To determine and describe sexual behaviour of individuals with a TSCI (that is, number of sexual partners, consistence of condom use, condom use at last sexual encounter).
- To determine and describe the mediating factors for HIV reduction including HIV-related knowledge, sex communication skills, self-efficacy, sex

negotiation skills, and time perspective among individuals with a traumatic spinal cord injury.

- To determine the predictive factors of risky sexual behaviour among individuals with a TSCI.

(b) To explore the socio-cultural issues that might increase individuals with a TSCI's vulnerability to HIV/AIDS.

- To explore individuals with a TSCI's perception of their engagement in safe or unsafe sexual practices and the issues that influence these.

(c) To review international and national commitments relating to disability and HIV/AIDS.

1.8 DEFINITION OF TERMS

Traumatic Spinal Cord Injury: can result from many different causes – including falls, road traffic injuries, occupational and sports injuries, and violence (WHO, 2013)

Non-traumatic Spinal Cord Injury: usually involves an underlying pathology – such as infectious disease, tumour, musculoskeletal disease such as osteoarthritis, and congenital problems (WHO, 2013).

Disability: is the umbrella term for impairments, activity limitations and participation restrictions, referring to the negative aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (Leonardi et al., 2006).

Paraplegia: This term refers to impairment or loss of motor and/ or sensory function in the thoracic, lumbar or sacral (but not cervical) segments of the spinal cord, secondary to the damage of neural elements within the spinal canal. With paraplegia, arms functioning is spared but depending on the level of the injury, the trunk, legs and pelvic organs may be involved. (Kirshblum *et al*; 2011).

Rehabilitation: this is a process aimed at enabling an impaired person to reach an optimum mental, physical and/ or social functional level, thus providing her or him with the tools to change her or his own life. It can involve measures intended to compensate for loss of function or functional limitation and other measures intended to facilitate social adjustments or readjustment (WHO, 2001).

Risky sexual behaviour: defined as early initiation of sexual intercourse, unprotected sex or sex with multiple partners (Center for Disease Control and Prevention, 2008).

HIV risk factors: are factors associated with a likelihood that an individual may become infected with HIV e.g. unprotected sex, multiple partnerships, lack of condom use, sex before age of 15 (UNAIDS, 2007).

HIV vulnerability factors: are factors outside the control of an individual that reduce his or her capacity to avoid HIV infection e.g. lack of HIV knowledge and skills (UNAIDS, 2007)

Spinal Cord: The spinal cord is the part of central nervous system consisting of nerve cells and bundles of nerves that connect the brain with all parts of the body (Hampton & Marshall, 2000).

Spinal cord injury: A temporally or permanent deficit in sensory motor and bladder and bowel function which occurs as a result of pathology or traumatic lesion of neural elements in the spinal canal. SCI causes varying degree of loss of motor, sensory function below the level of the injury depending on the extent of the injury (Hampton & Marshall, 2000).

Tetraplegia/ Quadriplegia: this term refers to impairment or loss of motor and /or sensory function in the cervical segments of the spinal cord due to the damage of neural elements within the spinal canal. Tetraplegia/ Quadriplegia result in impairment of function in the arms as well as typically in the trunk, legs and pelvic organs, including the four extremities. It does not include brachial plexus lesions or injury to peripheral nerves outside the neural canal (Kirshblum et al., 2011).

1.9 ABBREVIATIONS USED IN THE THESIS



AIDS:	Acquired Immune Deficiency Syndrome
CDC:	Centers for Disease Control and Prevention
CRPD:	Conventions on the rights of people with disabilities
HIV:	Human Immunodeficiency Virus
ICF:	International Classification of Functioning, Disability and Health
IDU:	Injecting Drug User (or use)
MDG:	Millennium Development Goals
NGO:	Non-governmental organisation
QASA:	Quadriplegic-Parra Association of South Africa

SSA:	Sub-Saharan African
SRH:	Sexual and Reproductive Health
SRHR:	Sexual and Reproductive Health Rights
STDs:	Sexual Transmitted Diseases
STIs:	Sexual Transmitted Infections
TSCI:	Traumatic Spinal Cord Injury
UNAIDS:	United Nations Programmes on HIV/AIDS
UNICEF:	United Nations Children's Fund
WHO:	World Health Organisation



1.10 OUTLINE OF THE THESIS

Chapter One introduced the study and highlighted the importance of examining the behavioural factors contributing to the risk and vulnerability to HIV/AIDS among individuals with Traumatic Spinal Cord Injury (TSCI) in South Africa. The overall aim, objectives and significance of the study is also outlined in this chapter.

Chapter Two presents a review of the relevant literature to HIV/AIDS and TSCI. An overview of HIV/AIDS in the context of disability is provided. A review of the policies guiding disabilities is also provided. Finally, the conceptual framework for the study is outlined.

Chapter Three gives a description of the setting in which the study was conducted. A description of the study population and sample is given, in addition to the methods used to

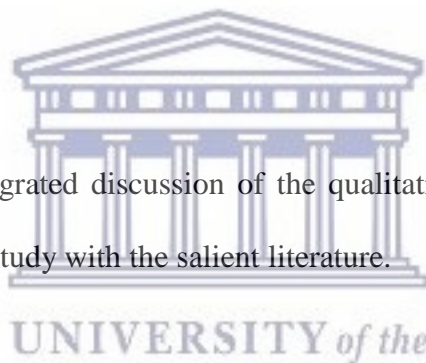
collect data. The data analysis is provided and the chapter concludes with an outline of the ethics that guided the study.

Chapter Four presents the results of the statistical analysis that attempted to assess the behavioural factors that could contribute to the risk and vulnerability to HIV infection among individuals with a TSCI. The behaviours that could contribute to risk of HIV and the mediating factors for HIV reduction are outlined. The results are complimented with tables and figures.

Chapter Five outlines the findings of the content analysis of the individual interviews in an attempt to explore the socio-cultural issues that might increase individuals with a TSCI's vulnerability to HIV/AIDS.

Chapter Six presents an integrated discussion of the qualitative and quantitative data and compares the findings of this study with the salient literature.

Chapter Seven provides a summary and conclusion of the study. In addition, limitations and recommendations are highlighted.

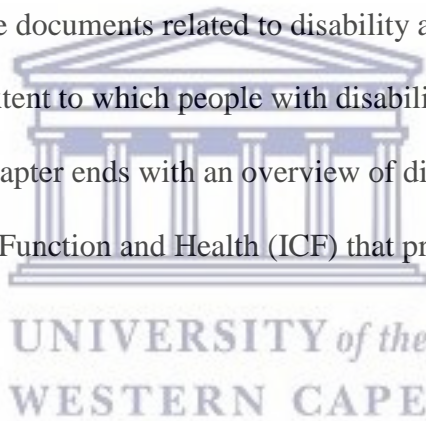


CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCCION

The nature of this study is very broad taking into consideration the complexities related to the resultant disability of traumatic spinal cord injuries, and the issues relate to the issues of sexuality in the context of the resultant disability. Therefore, this chapter will briefly outline the incidence of traumatic spinal cord injuries broadly first to outline the impact therefore on the individual. Thereafter the issues of sexuality and HIV/AIDS in the context of the resultant disability after sustaining a traumatic spinal cord injury will be reviewed. Following this a desktop review of the available documents related to disability and HIV/AIDS is provided with the aim to examine the extent to which people with disabilities in the context of HIV/AIDS is included. The chapter ends with an overview of disability models and the International Classification of Function and Health (ICF) that provided a theoretical framework for the study.



2.2 TRAUMATIC SPINAL CORD INJURIES

A spinal cord injury has been described by the World Health Organisation (WHO) as “a medically complex and life-disrupting condition” (WHO, 2013). It is an injury to the spinal cord and the damage to the cord could either be due to a traumatic or non-traumatic event. Traumatic events include among others road traffic accidents, gunshots, assaults, falls and sports related injuries while non-traumatic events include tumours, spinal stenosis or vascular incidents. The incidence and prevalence of persons with spinal cord injury is on the rise (Hagen, Rekand, Gilhus & Grønning, 2012; Wyndaele & Wyndaele, 2006). The rising tide of

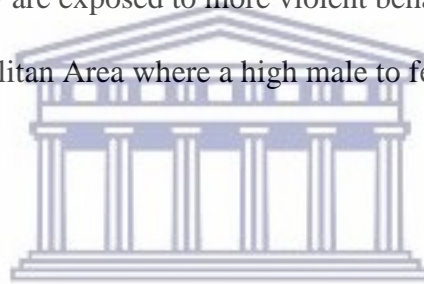
this physical health condition globally has been associated with an increase in motor vehicle injuries and crime- related cases.

Global estimates of the spinal cord injuries range from 10 to 80/ million population (Singh et al., 2014). The incidence rates for traumatic spinal cord injuries (TSCI) varied across the major world regions and Cripps et al. (2011) reported 40 per million in North America, 16 per million in Western Europe, 15 per million in Australia, 25 per million in the Asia – Central, 21 per million in Asia South, 19 million in Caribbean, 19 per million in Latin America Indian, 24 per million in Latin America Central, 25 per million in Latin America Southern, 29 per million in Sub- Saharan Africa Central and 21 per million in Sub-Saharan Africa East. The sub-Saharan region on the African continent has produced limited publications on TSCIs and up to 7 years ago was rarely mentioned in worldwide reviews (Draulans, Kiekens, Roel, & Peers, 2011). Several studies have emerged in Africa in recent years, namely, Nigeria (Obalum, Giwa, Adekoya-Cole, & Enweluzo, 2009), Ethiopia (Biluts et al., 2015), Botswana (Löfvenmark et al., 2015) and Ghana (Ametefe et al., 2016). A recent prospective survey done in South Africa (Joseph et al., 2015) indicated the incidence rate of 75.6/million population that was the highest in the world.

As the incidence rates for TSCI vary from region to region, so does the causes of these TSCI's vary. The main cause of TSCI in developed countries were reported to be road traffic accidents (Knútsdóttir et al., 2012) while the main cause in developing countries was reported to be related to violence (Cripps et al., 2011). In a prospective study done in South Africa, assaults (violence) was reported as the main cause of TSCI (Joseph et al., 2015). These trends are however changing as road traffic accidents seem to be on the increase in Sub-Saharan

Africa as reported by Löfvenmark et al. (2015) in Botswana and by Draulans et al. (2011) in Nigeria, Senegal, Sierra Leone and Zimbabwe. The increased rate of TSCI due to road traffic accidents in Africa were attributed to the increased number of vehicles in the absence of improved infrastructure and lack of safety belts in vehicles (Draulans et al., 2011).

As far as trends related to TSCI are concerned, higher incidence rates for males as compared to females has been reported all over (Wyndaele & Wyndaele, 2006). Wyndaele & Wyndaele (2006) attribute this trend to the fact that traditionally females in lower income countries are often at home while males are often activities with higher risks associated with it in the working environment and they are exposed to more violent behaviour. This same trend was observed in the Cape Metropolitan Area where a high male to female ratio was reported by Joseph et al. (2015).



Hampton and Marshall (2000) noted that a traumatic spinal cord injury resulting in severe traumatic disability mainly affects young people. Noonan et al. (2012) also reported that spinal cord injuries mainly affects young adults although an increase in the average age has been observed. In South Africa, researchers reported that those sustaining a traumatic spinal cord injury is most likely to be between 20 and 30 years of age (Joseph et al., 2015; Sothmann et al., 2015). The resultant disability due to this type of injury is mostly considered permanent (WHO, 2013). The consequences of a spinal cord injury are multi-faceted and multi-factorial in nature. Not only does the spinal cord injury lead to disability and result from trauma to the spinal cord, but it further presents in a very individualised and patient-specific manner (Rauch, Baumberger, Moise, von Elm & Reinhardt, 2011). 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. Since the development of modern, comprehensive, evidence-based rehabilitation and medical care, persons with spinal cord injuries generally live longer and thus age with their disability.

Since the survivors of SCI in South Africa is often of the male gender, between 16-30 years of age and of a poor socio-economic background, the expectation is that they still have future prospects of living a long life with very few possibilities of returning to the highest level of functioning, namely social integration, but specifically return to productive living. However, due to the characteristics of these survivors, it is also assumed that they are at risk for engaging in risky behaviours such as addictive substances and unprotected sex as their able-bodied counterparts. Conditions associated with an increase in mortality in later life, e.g. diabetes mellitus, tobacco addiction, hypertension, cardiovascular disorders and sexually transmitted diseases, have been identified in South Africa to be influenced by behavioural factors (Peltzer, 2000). It is therefore assumed that adolescents and young adults with spinal cord injuries are also at risk as is the general population. Eide et al. (2011) indeed reported that many of the key global risk factors for contracting HIV affect the disabled population disproportionately.

Spinal cord injury encompasses several chronic conditions and secondary complications, e.g. paralysis, immobilization, pressure sores and urinary tract infections. The consequences of a spinal cord injury are multi-faceted and multi-factorial in nature (Rauch, Baumberger, Moise, von Elm & Reinhardt, 2011). Sustaining a SCI not only causes major changes to individual's

physical and functional independence but also extended rehabilitation period means the patient's personal life style is similarly disrupted while the patient learns simple tasks or musters new skills, he must adjust to and accommodate to life with SCI (Kennedy et al, 2012). Survival after the spinal cord injury is dependent on access to adequate care and rehabilitation and differs substantially between countries. The increased long-term survival in the spinal cord injured population as a whole requires us to consider both new challenges during the post-acute rehabilitation phase and during life-long follow-up. Age-related issues in persons with spinal cord injuries are still not sufficiently elucidated.

In conclusion, it is evident that traumatic spinal cord injuries are of importance and concern in both the developed and the developing contexts. It is also clear that an increase of traumatic spinal cord injuries is seen and mostly due to motor vehicle accidents and crime-related incidents. Of importance to note is the fact that in South Africa, the individual sustaining a traumatic spinal cord injury, is most likely to be of a younger age (16 – 30 years) male, and with a poor socio-economic background. When looking at these characteristics, it can easily be assumed that the survivors of a traumatic spinal cord injury in South Africa would be prone to engaging in risky behaviours such as alcohol, drug use and risky sexual behaviours, similar to their able-bodied counterparts.

2.3 SEXUALITY AND HIV/AIDS IN THE CONTEXT OF DISABILITY

2.3.1 SEXUALITY AND DISABILITY

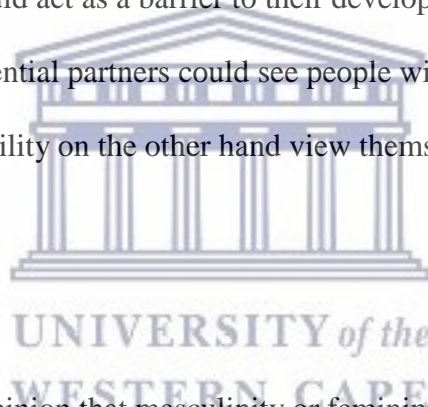
Sexuality represents a whole range of behaviours, attitudes and activities in addition to influencing gender identity (Robinson et al., 2011; Sakellariou Simo Algado, 2006).

Sakellariou (2006) stated that sexual expression is a fundamental right of every individual.

Robinson, Forrest, Pope-Ellis and Hargreaves (2011) also state that sexuality is an inherent and multi-faceted aspect fundamental to an individual's being. They further argue that a common mistaken belief is the view that sexuality only included sexual intercourse and other physical acts and that literature tends to limit sexuality to the physical abilities of the individual.

Ostrander (2009) is of the opinion that encounters of a sexual nature are complex even under ideal circumstances and therefore an illness or disability adds to these complexities. This researcher further states that both the individual and their partners' viewpoints regarding sexuality and performance could act as a barrier to their development of sexual encounters.

Tepper (2000) agrees that potential partners could see people with disabilities as being asexual and those with a disability on the other hand view themselves as being less sexually desirable.



Many researchers are of the opinion that masculinity or femininity are often denied or refused to people with disabilities, issues which are taken for granted by the non-physically challenged population (Sakellariou, 2006; Milligan & Neufeldt, 2001; Tepper, 2000). It is indeed recognised that the sexual lives of people with disabilities have traditionally been ignored and even stigmatised (Esmail, Darry, Walter & Knupp, 2010; Neufeld, Klingbeil, Bryen, Silverman & Thomas, 2002). These researchers are of the opinion that the topic of sexuality in the context of people with disability was mainly side-stepped because it was a difficult topic to address in addition to its forbidden nature. Scholars have acknowledged that up to today, sexuality as a form of pleasure is still not understood or accepted for people with disabilities (Esmail et al., 2010; Tepper, 2000). It is therefore clear that the socio-cultural

beliefs regarding sexuality and disability might be more restricting than the physical impairment itself (Mayers, Heller & Heller, 2003).

Sexuality following a spinal cord injury is influenced and complicated by significant physiological impairment in addition to the effects of emotional distress, loss of self-esteem and feelings of sexual inadequacy (Fischer et al., 2002). Ostrander (2009) emphasized that individuals with a spinal cord injury remain sexual beings and that they can continue to lead sexually satisfying lives. This author further reiterated that there are two issues that an individual with a spinal cord injury might struggle with about their sexuality. Firstly, a struggle with the reconciliation of their sexual experiences before and after the injury. One of the important aspects of the comparison of before and after injury, is the fact the loss of genital sensation and the inability to experience an orgasm. Secondly, individuals with a spinal cord injury struggle with both internal and external perceptions which become barriers to forming a sexually intimate relationship. Potgieter and Khan (2005) argued that the silence around sexuality and disability is nowhere more deafening than in the area of adolescents with a spinal cord injury.

Ostrander (2009) referred to a historical review of sexuality following a spinal cord injury done by Wilmuth in 1987 and highlighted that this review discussed four main themes, i.e. “sexual response cycle, reproductive functioning, sexual behaviours and adjustments, and sexual counselling after SCI”. The main findings of this review was that men are more affected than women with regards to reproductive functioning, that men experience lower sperm counts in addition to decreased sperm mobility following a spinal cord injury. It was further highlighted that individuals with a spinal cord injury remain sexually interested.

Researchers have made it clear however that on closer inspection of the literature pertaining to sexual functioning after a spinal cord injury, it becomes clear that very few studies investigate sexual functioning and the sex life of SCI women compared to that of SCI men (Kreuter, Taft, Siösteen & Biering-Sørensen, 2011).

In conclusion, when an individual has a disability, the perception is that he/she is asexual. It also evident that the sexual lives of people with disabilities are largely ignored and sometimes even stigmatised. As is the case with disability in general, the same applies to individuals who survived a traumatic spinal cord injury with a resultant physical disability. Although sexuality of individuals with a TSCI has received attention in the literature, the sex life of women with a TSCI is limited and should be explored further.

2.3.2 HIV/AIDS AND DISABILITY

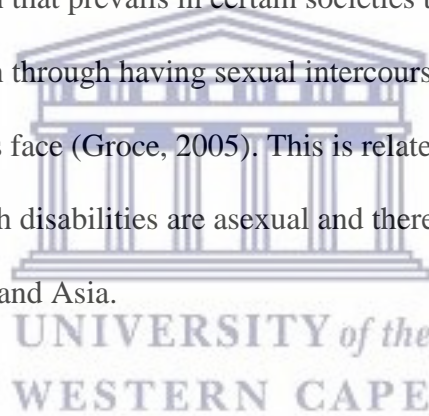
Groce (2005) described one of the characteristics of the HIV/AIDS epidemic as the effect it has on the most vulnerable populations. According to her this population, those living with a permanent disability, whether it is physical, sensory, intellectual or mental, has been almost completely ignored, even though they are equally at risk of being exposed to the known risk factors for HIV. She further stated that a worrying feature of the HIV/AIDS epidemic has been the effect it has on vulnerable populations such as the disabled.

The risk factors for HIV/AIDS, such as poverty, illiteracy, stigma and marginalization are well established and is exactly the same for those living with a disability (Groce, 2005).

Researchers have indicated that the behavioural risk factors for HIV associated with sexual

activity are exactly the same for the general population and those with disabilities (Mulindwa, 2003). Choquet, DuPasquier, Pediasevsky and Manfredi (1997) also pointed out that in their study adolescents with a physical disability reported higher rates of sexual intercourse and more sexual partners than their able-bodied peers.

In addition to the risky sexual behaviours indicated above, it has been reported that both women with a disability are also very vulnerable and are as much as three times more likely to be raped than those without a disability (Groce, 2005). This author further pointed out that men and boys with disabilities face the same challenges of rape and sexual abuse as their female counterparts. The myth that prevails in certain societies that an HIV-positive man can free himself from the infection through having sexual intercourse with a virgin adds to the risk that those with disabilities face (Groce, 2005). This is related to the myth or misconception that people with disabilities are asexual and therefore virgins. These myths are especially prevalent in Africa and Asia.



Due to the myth of asexuality of individuals with a disability, appropriate information with regards to the prevention of HIV is not given to them (Eide et al., 2011). In South Africa it has been reported that many individuals with disabilities are often excluded from the general HIV/AIDS campaigns (Rohleder et al., 2010). It has further been reported that the levels of knowledge with regards to HIV/AIDS among individuals with disabilities are low, not only in South Africa, but also in other African countries (Wazakili, Mpofu & Devlieger, 2006; Munthali, Mvula & Ali, 2004). Anderson and Beutel (2007) argued that information and knowledge is a crucial and important aspect in the prevention of HIV/AIDS. Issues such as the inadequate training and anxiety of staff/teachers to raise the issue of sexuality and

HIV/AIDS with disabled persons is another issue that is raised in literature (Rohleder & Swartz, 2009).

Literature with regards to the prevention of HIV/AIDS efforts for people with disabilities are discussed broadly in literature and distinct disability groups such as survivors of a traumatic spinal cord injury are not reported on specifically. It is clear that despite the notion that those with a disability is asexual, they are at great risk and are indeed vulnerable to HIV/AIDS. The crucial elements of knowledge and information in the prevention of HIV/AIDS for people with disabilities are very clear.

2.4 REVIEW OF INTERNATIONAL AND NATIONAL COMMITMENTS/POLICIES RELATING TO DISABILITY AND HIV/AIDS

Dye (2001) stated that policies are broad statements of goals, objectives and means that creates frameworks for activity. These decisions are usually taken by individuals responsible for a distinct policy area. Dye (2001) further stated that public policy or government policy is usually defined as “whatever governments choose to do or not to do”. According to Buse et al. (2008) policies are usually in the form of explicit documents, but it could also be unwritten or implicit.

Judge (2002) stated that due to the history of the HIV/AIDS policy milieu in South Africa, it is important to understand the varying and competing representations of HIV/AIDS at the policy level. He further stated that both government and policy makers have the public

platform to shape and communicate specific metaphors with regard to HIV/AIDS. Judge (2002) however is of the opinion that as long as representations of HIV/AIDS remain a battlefield of ideological and political persuasions, there will be a lack in attempts to adequately respond to the practical requirement of effective and reasonable prevention, treatment and care strategies.

The fact that people with disabilities in the context of HIV/AIDS have not been adequately addressed has been recognised (Gertholtz, Grant & Hanass-Hancock, 2010). The report completed by these authors clearly stated that even though the human rights dimensions of HIV has been recognised, people with disabilities have still not been recognised to be a key population at a higher risk of HIV/AIDS. A desktop review of all the available documents related to disability and HIV were therefore conducted. The main aim of this review was to examine the extent to which people with disabilities in the context of HIV were included. The documents reviewed included international and national documents.

2.4.1 Convention on the Rights of Persons with Disabilities (United Nations, 2006).

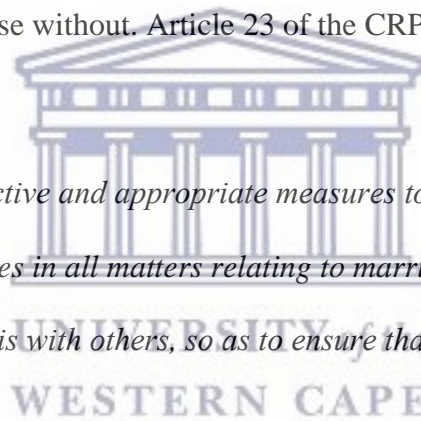
The 1980's were declared the Decade of Disabled People by the United Nations and on recommendation from a group of experts an international convention was developed on disability and human rights. An Ad Hoc Committee was established in 2001 by the United Nations with the task to examine if a convention focussing on the rights of persons with disability was needed. The committee then negotiated the content of the convention with the Member States of the UN and finally produced the Convention on the Rights of Persons with Disabilities (CRPD). The CRPD, a treaty instrument, is the first binding international dealing

with the rights of persons with disabilities. All the member states of the UN are obliged to make sure that all the provisions of the CRPD are included into its laws, once signed and ratified. South Africa has signed and ratified the CRPD but to date has not fully implemented the measures as set out in it (United Nations, 2006).

HIV and/or AIDS are not explicitly referred to in the CRPD (in either the definition of disability or the articles) but it is implied and recognized to a certain extent in some of its articles by referring to issues related to sexual and reproductive health.

The convention acknowledges that relationships (in all forms) are as important for people with disabilities as it is for those without. Article 23 of the CRPD (Respect for home and family) states that:

“States Parties shall take effective and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships, on an equal basis with others, so as to ensure that...:”



Sexual and reproductive health is specifically addressed Article 25 of the CRPD (Health) states that all people with disabilities have the rights to the highest standard of health without discrimination on the basis of their disability.

“Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.”

Article 26 of the CRPD (Habilitation and Rehabilitation) urges all its member states to include peer support in their efforts to ensure full inclusion and participation for people with disabilities:

“take appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life”

This article clearly states “*all aspects of life*” and therefore should be assumed that peer support in the area of sexual and reproductive health issues should be included.

2.4.2 Census 2011: Profile of persons with disabilities in South Africa (Statistics, South Africa)

It is recognised that one of the key data sources for government planners and policymakers, are censuses. In addition, the information gained from a census can also be used to monitor national priorities and achievements such as the Millennium Development Goals (MDGs). The 2011 census report on the “Profile of persons with disabilities in South Africa” gives a comprehensive overview of persons with disabilities in the country in terms of their demographics, socio-economic and health status. This report is made up of several chapters (9) and outlines various aspects related to disability such as how disability has been measured, the prevalence and patterns of disability, education and income, access to housing and basic services and assistive devices.

As was the case with the CRPD HIV and/or AIDS are not explicitly mentioned. It is however implied in the second chapter that deals with the “Disability policy framework in South Africa” when referenced is made to relationships and sexuality:

“2.5 Sexuality and marriage framework for persons with disabilities”

In this section reference is made to article 23 of the CRPD (Respect for home and family):

“This legislative framework recognises that relationships are as important for persons with disabilities as for everyone else.”

In addition, issues related to discrimination are also highlighted which could have implications for the persons with disabilities’ vulnerability to HIV/AIDS:

“Considered in some societies as less eligible marriage partners, women with disabilities are more likely to live in a series of unstable relationships...”

Although this document is addressing accessibility by referring to articles 19 and 28 of the CRPD and states that the promotion of accessibility of services should be provided such as medical facilities, attention is only drawn to the lack of access to assistive devices:

“Despite the existence of numerous legislations pertaining to access, many persons with disabilities still have unmet needs for assistive devices, limiting their inclusion in many activities. This is especially prevalent in communities that are under-resourced.”

2.4.3 World Report on Disability (World Health Organisation, 2011)

The World Report on Disability was produced by the World Health Organisation and the World Bank Group. This report is an effort to provide evidence for policies and programmes to improve the lives of people with disabilities. These two world bodies recognised that

people with disabilities, when compared to people without disabilities, experience barriers in many areas such as health, education, employment, transport and information. As a result of these barriers faced, people with disabilities therefore have poorer health, lower education, less employment and subsequently higher rates of poverty.

This report specifically mentions HIV/AIDS in the context of attaining the Millennium Development Goals (MDGs) but also in the context of people with disabilities. In the chapter of “General Health Care” the report addresses sexual and reproductive health services and clearly states that these services should include issues such as “*preventing and treating sexually transmitted infections including HIV/AIDS*”. The report however also recognizes that people with disabilities *are more likely to be excluded from sex education programmes*.

In the same chapter, HIV/AIDS in the context of disability and Africa specifically is addressed under targeted interventions for people with disabilities at a higher risk. The report also drew attention to the importance of the training of people with disabilities to offer education to others:

The participatory and inclusive approach proved effective in training young people with disabilities as well as peer educators and outreach workers.

The report also drew attention to the CRPD under sexual and reproductive health of persons with disabilities. It clearly highlighted that evidence exist *that people with disabilities are sexually active and therefore the importance of access to sex education in an effort to promote sexual health and positive experiences of sex and relationships*.

The recommendations made by the World Report on Disability includes many stakeholders such as governments, world bodies (such as the UN), organisations for people with disabilities, people with disabilities and their families, and academic institutions too. These recommendations include issues such as access to systems and services, investment in specific programmes for people with disabilities, national disability strategies and the involvement of people with disabilities amongst others.

2.4.4 Draft First Country Report to the United Nations on the Implementation of the Convention on the Rights of Persons with Disabilities (Government Gazette, 2015)

In the draft of the First Country report to the UN on the implementation of the CRPD, the report acknowledges that people with disabilities are not a homogenous group, and that the voice of persons with disabilities have become stronger, but that access to services in some instances *deepened inequalities between able-bodied and disabled citizens*. The country report covers issues such as education for people with disabilities and mental health in much detail.

As was the case with the CRPD, the country report did not explicitly refer to HIV/AIDS other than that treatment guidelines are being developed. The inputs from the disability sector on Article 25 however draw attention to reproductive health:

“The strategy to ensure access to information to persons with disabilities is unclear with particular reference to reproductive health.”

In the country report it is acknowledged that certain issues such as weaknesses in governance, capacity constraints and lack of co-ordination within the disability sector have undermined a more methodical and orderly approach to the implementation of the CRPD.

2.4.5 South Africa's National Strategic Plan for HIV, Sexually Transmitted Infections (STIs) and TB (2012 – 2016)

In the preface of the National Strategic Plan for HIV, Sexually Transmitted Infections (STIs) and TB 2012-2016, the then deputy president of South Africa and chair of the South African National Aids Council, Mr Kgalema Motlanthe, noted that the publication of this plan indicates a significant milestone in the South African nation's "response to the dual epidemics of HIV and TB". He further asserted that the five-year plan is a reflection of the progress made in the understanding of the challenges presented by these two epidemics and the vision of all the stakeholders to reach their long-term vision of zero new HIV and TB infections (South African National AIDS Council, 2011). The KYE ("Know Your Epidemic") report and other epidemiological studies guided the NSP and these studies identified key populations. Within these key populations, most likely to be exposed to or transmit HIV and/or TB are "*persons with disabilities and mental disorders*" among others.

The NSP goals were to be achieved through interventions categorised in four strategic objectives. These strategic objectives include the following: Address social and structural drivers of HIV and TB prevention, care and impact; prevent new HIV, STI and TB infections; sustain health and wellness; and ensure protection of human rights and improving access to justice (South African National AIDS Council, 2011).

The term disability is referred to throughout the plan not specifically related to people with disabilities but in terms of the need to “*reduce significant deaths and disabilities due to HIV and TB*”.

In addition to people with disabilities being included in the term *key populations*, in sub-objective 2.4 of the NSP, i.e. to implement a comprehensive national social and behavioural change communication strategy with particular focus on key populations, it also states that “*This strategy must take into consideration the special communication needs of persons with disabilities, and also be targeted to traditional circumcision.*”

In the strategic objective 3, i.e. to sustain health and wellness, people with disabilities are specifically mentioned in terms of screening and testing:



“Persons with disabilities: Screening and testing programmes that focus on this group must use tailored interventions according to specific needs of persons with disabilities. Physical access to facilities and accessible communication is imperative and must be designed and implemented in partnership with organisations focusing on the needs of persons with disabilities”. (South African National AIDS Council, 2011 : p15).

Strategic objective 4 of the NSP is to “Ensure Protection of Human Rights and increase access to justice. Within this objective the constitutional right of access to health care and other social services are used as the starting point. Each objective, mentions key populations such as people with disabilities and states that:

“access to social services requires that interventions be planned and implemented in a manner that recognizes the specific needs of these groups and the social, cultural, legal, economic and other possible barriers to accessing services.”

In the sub-objective 4.2, i.e. to reduce discrimination in access to services, the focus is placed on the range of grounds on which access to HIV STI and TB services might be denied to individuals. These grounds include among others age, race and disability. One of the interventions highlighted under this objective is dealing with providing training to prevent unfair discrimination. Specific mention is made of the provision of training by both public and private bodies to include modules *“dealing with unfair discrimination, including a focus on the needs of persons with disability”*. In addition, included is the need for both local and provincial communication efforts to *“be tailored to reach particular communities or groups and the most vulnerable must be reached (such as persons with disabilities, sex workers and prisoners)”*.



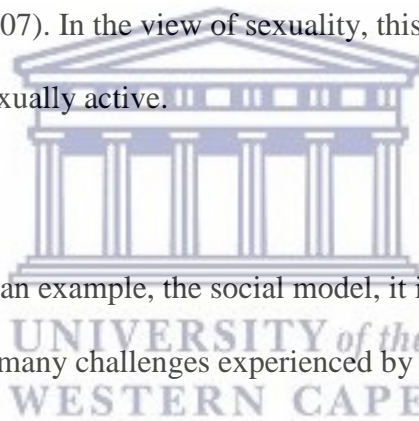
2.4.6 Summary

The rights of persons with disabilities have been recognised at both the local and international level in the last couple of years. The CRPD has caused an increased awareness to the rights of persons with disabilities and the need for member states to include them in various policies. The HIV epidemic is also taken seriously in South Africa and at the national level, policies addressing the all-inclusive care and management of people living with HIV/AIDS, including people with disabilities, have been introduced. The International Disability and Development Consortium (IDDC) and Disability Task Group (2016) however cautioned that despite the fact that the global response to HIV and AIDS has demonstrated “outstanding global

solidarity and shared responsibility”, stakeholders should reach out to those individuals “who have been left behind” and this include people with disabilities.

2.5 THEORETICAL FRAMEWORK OF THE STUDY

Attempts to understand the concept of disability has been made throughout history. Some of these models include the medical, social and human rights models. Pledger (2003) however pointed out that considerable difference exists between the old and new models of disability perspectives. The medial model for example regarded disability as a health and social welfare issue and as a result reduced people with disability to the “sick role” and therefore passive recipients of charity (Mont, 2007). In the view of sexuality, this therefore implies that people with disabilities may not be sexually active.




Some of the newer models, as an example, the social model, it is recognized that impairments are not the main source of the many challenges experienced by people with disabilities, but it is however the manner in which society reacts to them (Disabled People of South Africa, 2001). In addition, this model promotes inclusiveness, i.e. integration of people with disabilities in normal day to day activities. Bonnie (2004) however warns that although the social model highlights and focus on all the myriad of challenges faced by people with disabilities, sexuality and sexual health is one of the most fundamental exceptions.

Together with the social model, other ideas arose in the 1990s, such as the Rights and Independent Movements. People with disabilities were then viewed as an oppressed and disadvantaged group of society (Priestly, 2006). In South Africa, the disability rights

movement was strongly influenced by the experiences of people with disabilities living under the apartheid system, where all of them were discriminated against (Howel, Chalken & Thomas, 2006).

The WHO recognized the changes that occurred with regard to the conceptualisation of disability. This world body then developed a classification, hence the International Classification of Functioning, Disability and Health (ICF) framework was developed. This model presents a better understanding of the complex interaction between the features of the biological, psychological, cultural and social factors of disability.

2.5.1 The International Classification of Functioning, Disability and Health



Academics, clinicians and people with disabilities have all been involved in the lengthy process of development of the International Classification of Functioning, Disability and Health (ICF), in an attempt to explain disability. All aspects related to health and/or health relevant components of well-being are described in terms of *health domains and health-related conditions* by the ICF (WHO, 2001). The health-related domains are placed in two broad categories, i.e. functioning and disability, and contextual factors. Issues with regards to human functioning are categorized in three areas in the ICF: impairments, activity limitations, and participation restriction. The contextual factors of the ICF include both environmental and personal factors, in an effort to describe the impact the environment has on the experiences of people with disabilities. Despite this, the ICF does not provide a clear explanation of the intersect of sexuality and disability.

The ICF, like the models described above, also locates the challenges people with disabilities face outside the resultant effect of impairment, but in the relationship that these individuals have with both micro- and macro-level structures in the environment. According to Wazakili (2007), one can only make assumptions about both the positive and negative influences the environment has on the sexuality of people with disabilities. Wazakili (2007) further postulates that some of the micro-level factors may include issues such as risk-taking sexual behaviour of people with disabilities which in turn increase their vulnerability to the risk of HIV. On the other hand, macro-level factors include issues such as poverty, cultural beliefs about sexuality and/or disability, and lack of policies, all of which play a role in increasing people with disabilities' vulnerability to HIV risk.



2.6 SUMMARY OF THE CHAPTER

This chapter provided an overview of the literature with regards to traumatic spinal cord injuries, disability and sexuality and HIV/AIDS in the context of disability. It is evident from the literature that sexuality of people with disabilities and have been largely ignored and should be explored more. The current study is an attempt to fill the gap in the literature with regards to the sexuality of survivors of a traumatic spinal cord injury in the context of HIV/AIDS specifically. The lack of information, the low levels of knowledge and poor access to services with regards to prevention of HIV/AIDS for people with disabilities are a concern as it is clear that these individuals are indeed vulnerable and at risk of contracting HIV through risky sexual behaviours. This study is therefore an attempt to fill the gap in the literature with regards to the sexual risk behaviours and knowledge of survivors of traumatic spinal cord injuries.

CHAPTER THREE

METHODOLOGY

3.1. INTRODUCTION

In this chapter, the methods used to conduct the study are described. In particular, the settings, study design, study population and sample and data collection methods are presented. The chapter also outlines the data analysis for both quantitative and qualitative data. The chapter concludes with a presentation of the ethics adhered to for the study.

3.2. RESEARCH SETTING

The study was conducted in conveniently selected provinces in South Africa. South Africa has nine (9) provinces and has a population of approximately 56 million people (Figure 3.1). The provinces with the highest population density are Gauteng (24.0%), KwaZulu Natal (19.9%), Eastern Province (12.6%) and Western Province (11.3%).

The HIV prevalence in South Africa is influenced by the geographical distribution and locality (Shisana et al., 2014). Significant fluctuations are being noted in different provinces across South Africa. The HIV population survey of 2014 depicts the severity of the epidemic between provinces, with the highest incidence in KwaZulu–Natal (16.9%) and the Eastern Cape accounted for 11.2 %. The survey also revealed that HIV prevalence was significantly higher for metropolitan cities namely eThekweni in KwaZulu-Natal and Ekurhuleni in Gauteng followed by Buffalo city in the Eastern Cape (Shisana et al., 2014). A decline in the knowledge

levels and increased risky sexual behaviours were among the main reasons stated for the high incidence of HIV.

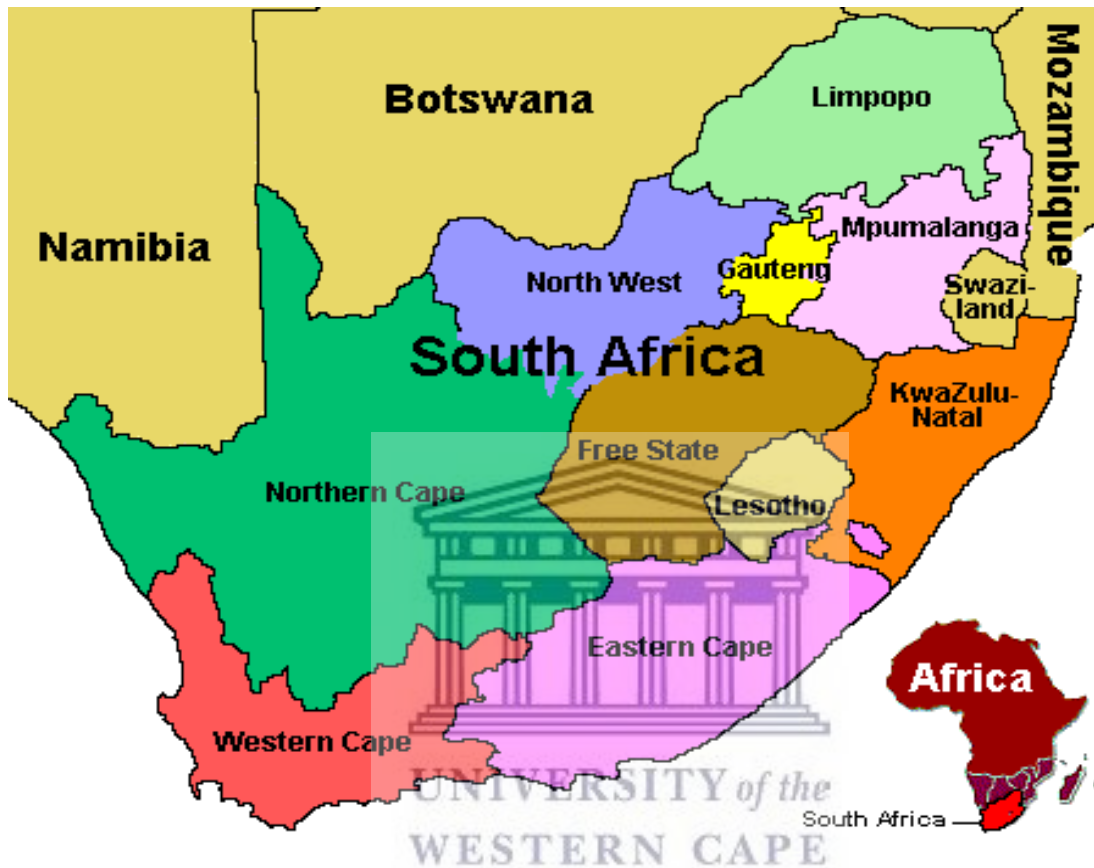


Figure 3.1 Map of South Africa showing the Provinces

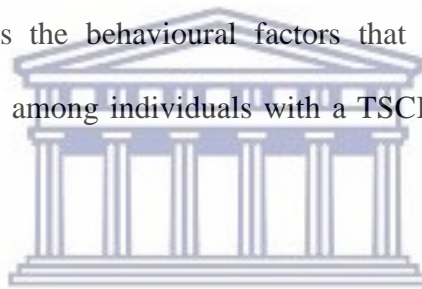
3.3. RESEARCH DESIGN

In this study, a mixed methods research design was used, using an explanatory sequential framework, in which first stage quantitative data will be analysed to inform the qualitative data collection approach. The purpose for combining a mixed method approach is that it is far more

diverse than designs rooted in one tradition and the integration of quantitative and qualitative data and can dramatically enhance the value of the mixed methods research (Fetters et al., 2013).

Walker, Spratt and Robinson (2004) highlight that using the two methods of research appears to offer a more comprehensive approach to finding answers to research questions. Furthermore, mixed methods provide a greater understanding and/or validation of results (Bazeley, 2007).

The main concerns of the quantitative paradigm are that measurement is reliable, valid, and generalizable in its clear prediction of cause and effect (Cassell & Symon, 1994). In the first phase of the study, to assess the behavioural factors that could contribute to risk and vulnerability to HIV infection among individuals with a TSCI a cross-sectional survey was used.



In addressing the qualitative second phase of the study to explore the socio-cultural issues that might increase individuals with a TSCI's vulnerability to HIV/AIDS, qualitative description (QD) was used as operative methodological approach. Qualitative research, as with QD, is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore social human problems and phenomena (Creswell, 1998). In QD, the aim is to better understand the perceptions and experiences attached to a particular phenomenon, such as how socio-cultural issues that might increase individuals with a TSCI's vulnerability to HIV/AIDS. QD is also useful in developing a conceptual basis of a phenomenon.

3.4 DATA COLLECTION METHODS

The data collection methods for the quantitative and qualitative phases of the study will be presented separately. The sampling strategy, instruments/methods used to collect the data and the data analysis for each phase is presented below.

3.4.1 TO ASSESS THE BEHAVIOURAL AND PROTECTIVE FACTORS THAT COULD CONTRIBUTE TO RISK AND VULNERABILITY TO HIV INFECTION AMONG INDIVIDUALS WITH SPINAL CORD INJURIES

3.4.1.1 Study population and sampling

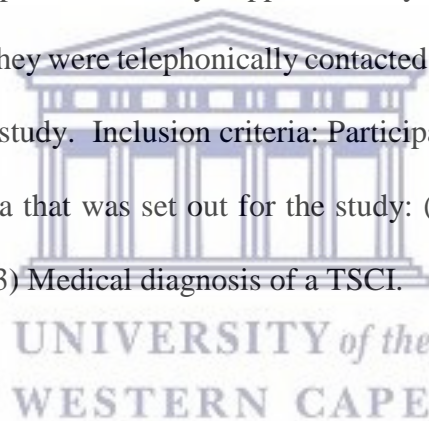
The Quad-Para Association of South Africa (QASA) was established in 1978 and at first only for the benefits of quadriplegics but later changed its constitution to include paraplegics. The organisation assists its members with mobility impairments to lead an independent life with a decent standard of living, in areas ranging from personal care and assistive devices to adequate skills development and employment. QASA is represented in various forums at all the levels of both the public and private sectors, to make sure that the needs of people with mobility impairments are addressed.

QASA has offices and centers in various provinces in South Africa. The following provinces with the highest prevalence of SCI was selected: Western Cape, Eastern Cape, Gauteng and KwaZulu Natal. The organization has provincial databases of all its members. Approximately 1 500 – 2 000 individuals are listed on this database. To calculate a reasonable sample size for this study, the Yamane formula was used to calculate a sample size. Yamane provides a simplified formula to calculate sample sizes (Israel, 1992).

$$n = \frac{N}{1 + N(e)^2} = \frac{1\,500}{1 + 1\,500(.05)^2} = 316$$

Therefore at least 316 individuals were needed to be included.

To ensure the protection of personal information as stipulated in the Protection of Personal Information (POPI) act (No 4 of 2013) (Buys, 2017), the organisation (QASA) sent out invitations to individuals in the respective provinces on their database to participate in the study. The contact details of those who indicated their consent to be contacted by the researcher was then approached to participate in the study. Approximately 330 individuals indicated their willingness to be contacted. They were telephonically contacted to arrange an appropriate time and place to participate in the study. Inclusion criteria: Participants were included if they met the following inclusion criteria that was set out for the study: (1) above 18 years of age (2), residing in the South Africa, (3) Medical diagnosis of a TSCI.



3.4.1.2 Data collection methods

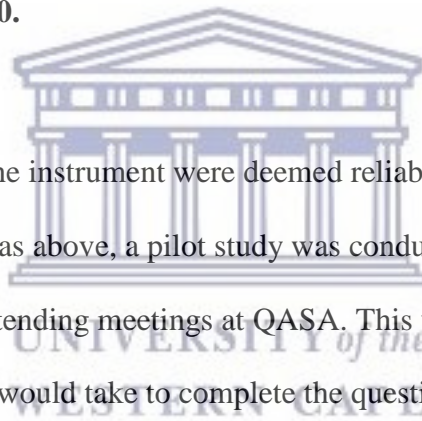
Data was collected by means of a self-administered questionnaire or an interview-administered questionnaire in the case of participants that did not have the full hand function. The questionnaire consisted of various sections and is described below:

- **Demographic information:** This self-constructed scale measured the demographic and socio-economic characteristics of the participants. Items included gender, age, and highest level of education. Level of spinal cord injury and awareness of programmes in their respective communities were also requested. Participants also indicated if they knew their HIV-status.

- HIV- KQ-18:** The HIV-KQ-18 is a self-administered scale (Carey & Schroder, 2002) that measures the knowledge of HIV transmission, prevention, and misconception about HIV infection. It consists of 18 items dichotomized into 1 = ‘True’ and 0 = ‘False’ or ‘Don’t Know’. A total score for each participant is constructed on a continuous scale by adding the number of correct answers ranging from 0 to 18 with higher scores indicating more knowledge of HIV/AIDS in heterosexuals with a low level of education (**Cronbach alpha coefficient = 0.75-0.89**).
- Sexual behaviour:** Sexual behaviour was assessed using a self-administered scale adapted from the sub-scale “*Sexual Activity*” of the Behavioural Risk Factor Surveillance System (BRFSS), developed by the Centre for Disease Control and Prevention (CDC) to collect data on risk behaviour that affect health status. This scale was used to measure the age of first sexual intercourse, condom use at first and last sexual contacts, and number of sexual partners. Individuals were requested to report whether they were sexually active (0 = No, 1 = Yes), age of sexual debut (0 = ≤ 14 years, 1 = > 14 years), lifetime sexual partners (0 = one sexual partner in the past 12 months, 1 = more than one sexual partner in the past 12 months), consistency of condom use (0 = Sometimes/Never, 1 = Always) and condom use at last sexual contact (0 = No, 1 = Yes).
- Sexual communication and negotiation skills:** Individuals were requested to respond to a series of questions assessing sexual communication and negotiation skills, adapted from the Assertive Sexual Communication Scale (Deiter, 1994). They rated each item using a five-point Likert scale ranging from ‘strongly agree’ to ‘strongly disagree’ across eleven items (internal consistency, $\alpha = 0.93$). Examples of items are: ‘I would want to know if my

partner has ever had a HIV test’, ‘Most of the time we do what my partner wants to do’. Higher scores indicate higher skills for communication and negotiation skills.

- **Self-efficacy to refuse sex:** This scale was designed to assess sexually active and sexually inexperienced individuals’ self-efficacy to refuse sex (Basen-Engquist et al., 1999). The scale consists of four items with a five-point Likert scale ranging from ‘very sure’ to ‘not very sure’. An example of items is: ‘...imagine your partner, he or she wants to have sex but you don’t feel ready, how sure are you could keep from having sex until you feel ready?’ Higher scores indicate higher perceived ability to refuse sex. **Internal consistency (Cronbach alpha) was 0.70.**



Although the components of the instrument were deemed reliable and valid as indicated with internal consistency measures as above, a pilot study was conducted among 20 individuals with a traumatic spinal cord injury attending meetings at QASA. This was done to determine the clarity of the wording and the time it would take to complete the questionnaire. Needed changes were made before it was administered.

It was found that the time taken to complete the questionnaire ranged from 30 to 45 minutes.

3.4.1.3 Data analysis

The statistical package for the Social Sciences (SPSS) version 21 was used for data analysis. Means (standard deviation), medians and relative frequencies are presented for descriptive data. Chi-square tests were used for dichotomous nominal data and the student’s independent sample t-test for continuous data. Gender differences in the different provinces was measured

by odds ratio (OR) with 95% confidence interval. A p-value of <0.05 was considered significant. The 95% CI was used to describe significance and size of difference for continuous data. Separate binary logistics analysis was done to assess which of the selected factors are associated with risky sexual behaviour. The forced entry method approach was used to determine which of these factors have the greatest productive power to predict sexual risk behavior.

3.3.2 OBJECTIVE 2: TO EXPLORE THE SOCIO-CULTURAL ISSUES THAT MIGHT INCREASE INDIVIDUALS WITH TRAUMATIC SPINAL CORD INJURIES' VULNERABILITY TO HIV/AIDS

Population and sample:

The selection of individuals for qualitative research that would assist the researcher to understand the research problem has been emphasized as an important issue by Creswell (2003). Patton (1990) has described all types of sampling in qualitative research under the umbrella term “purposive sampling”. The population for this phase included all participants who agreed to participate in the first phase of the study. The researcher therefore, decided to approach individuals from the all four provinces to participate in this study. No “a priori” sample size was developed, but participants were recruited and interviews continued until saturation has been reached of all the categories.

Data collection methods:

After consent was given by participants to participate in this phase of the study too, consenting participants were visited by the researcher for data collection in the environment indicated by

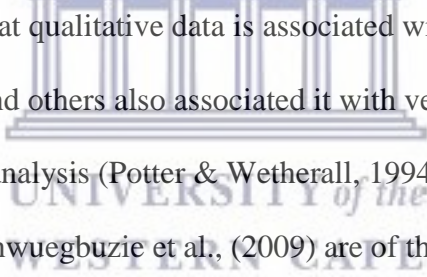
the participant. The researcher conducted face to face exploratory interviews with participants. In-depth, semi-structured interviews as well as observations were used for all participants in a similar order and format to extract similarities and compare answers. By approaching the same issue from different angles, it gave the researcher an understanding of each individual's experience. Although there were some established general topics for investigation with possible prompts to help guide the conversation, this method allowed for the exploration of themes and ideas that emerge during the interview.

Trustworthiness of the qualitative data: trustworthiness of qualitative research generally is often questioned by positivist, 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/ generalisability), **dependability** (in preference to reliability) and **confirmability** (in preference to objectivity).

Credibility of the qualitative data will be achieved through membership checking. This involves asking the informant to read transcript of the dialogue in which they might have been participated. The emphasis was on whether the informants 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 can be verified against others and, ultimately, a rich picture of the attitudes, needs or behaviour of those under scrutiny may be constructed based on the contributions of a range of people (Shenton, 2004). Transferability of

the qualitative were 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 were 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 will be reported in details (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.

Data Analysis



It is clear from the literature that qualitative data is associated with many assumptions and procedures. Thomas, (2006) and others also associated it with very specific analytic approaches such as discourse analysis (Potter & Wetherall, 1994), grounded theory (Strauss & Corbin, 1998). However, Onwuegbuzie et al., (2009) are of the opinion that transcript-based analysis is the most rigorous method. Patton (1990) also states that qualitative data analysis is inductive because patterns and themes emerge from the data rather than being imposed on them. Thus, the analysis of the interviews started with the transcription of the information from the audiotape recordings to produce manuscripts. A comparison was made with the notes taken during the interviews to verify the accuracy. Familiarization and immersion with the data followed by reading the through the transcripts several time by the researcher. The introduction of themes was an inductive process as the transcripts were read through several times. With an emphasis on the emergence of the ideas and themes. Coding were done as data was marked as it relates to one or more of the themes. During the

evaluation stage of the analysis, broader categories were created and data was examined several times.

The analysis of the interviews started with the transcription of information from the audiotape recordings to produce a manuscript. Transcripts were read through several times by the researcher, with emphasis on the emergence from the ideas of themes. Notes was made throughout the reading of the transcripts. Data was coded in themes, followed by the creation of broad categories of emerging themes which fit together.

The analysis was done by reading through the transcripts, again and again, making as many headings as necessary to describe all aspects of the content. In addition, grouping of the themes into broader categories were done in order to reduce the number of themes or small categories; for instance, very similar headings were being conflated to come up with one. However, the researcher focused the emphasis on searching for categories that have internal convergence and external divergence, which means that the categories were internally consistent but distinct from one another (Marshall and Rossman, 1995). After the derivation of themes, an independent researcher was asked to read through the transcripts and generated themes, thus increasing the validity and reliability of the categorizing.

3.4 ETHICS

Permission and ethics clearance to conduct the study was obtained from the Senate Higher Degrees Committee and Senate Research Grants and Study Leave Committee at the University of the Western Cape (UWC) registration no: 13/10/29 (Appendix 1). Permission was also

sought from the National office of the Quadriplegic Association of South Africa (QASA) (Appendix 2). To ensure the protection of personal information as stipulated in the Protection of Personal Information (POPI) act (No 4 of 2013) (Buys, 2017), the organisation sent out invitations to individuals on their database to participate in the study. Once consent was given by the individuals with a TSCI, the researcher sent out information sheets (Appendix 3a, b and c), consent forms (Appendix 4a, b and c) and contact details to those willing to participate. The study was conducted according to ethical practices pertaining to the study of human subjects as specified by the UWC and Faculty of Community and Health Sciences Research Ethics Committee of the UWC. The following guidelines were observed: The purpose of the study was clearly explained by the researcher to the participants and relevant authorities **(Information sheet attached). Information sheets was available in English, Afrikaans and Xhosa.** Signed, written informed consent was sought from all participants. **Consent forms were also available in English, Afrikaans and Xhosa.** 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. Identification codes using numbers were used on data forms to ensure anonymity. Information obtained from participants was for the study only and were handled with confidentiality. Pseudonyms were used to protect participants' identities when results were published. The researcher collected the questionnaires personally and was responsible for ensuring their storage in a locked and secure place. All information will be kept for a minimum of five years where after which it will be destroyed. No perceived risks were encountered in the study. The findings of the study will be made available to all the relevant stakeholders.

3.9. SUMMARY OF THE CHAPTER

In this chapter, the methodology used to conduct the study was presented. This included the settings; study design; population and sampling methods; data collection methods, instruments and analysis for each objective procedures and ethical considerations. The results of the study are presented in the next two chapters.

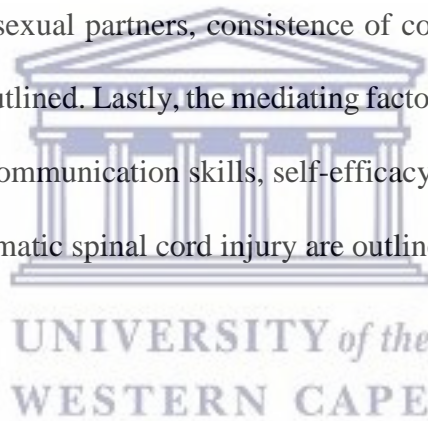


CHAPTER 4

BEHAVIOURAL FACTORS CONTRIBUTING TO RISK AND VULNERABILITY OF HIV AMONG INDIVIDUALS WITH A TSCI

4.1 INTRODUCTION

This chapter focuses on addressing the first objective of this study. Results of the statistical analysis are presented on in to attempt to assess the behavioural factors that could contribute to the risk and vulnerability to HIV infection among individuals with a TSCI. This chapter therefore describes the sexual behaviour of individuals with a TSCI. Factors related to risky sexual behaviour, number of sexual partners, consistence of condom use and condom use at last sexual encounter will be outlined. Lastly, the mediating factors for HIV reduction including HIV-related knowledge, sex communication skills, self-efficacy and sexual negotiation skills, among individuals with a traumatic spinal cord injury are outlined.



4.2 CHARACTERISTICS OF STUDY POPULATION

Three hundred and thirty (330) individuals with a TSCI from QASA's data base indicated their willingness to be contacted for participation in the study. Two hundred-and-forty-two (242) individuals finally agreed to participate, therefore yielding a response rate of 73.3%. The study sample consisted of 138 males (57%) and 104 females (43%) with a mean age of 33.95 (SD=10.280). The study sample further included 51.7% (n= 125) who were paraplegic from the four provinces. The biggest presence (53.3%) of the participants were Black African and the majority (80%) lived in urban areas. A small percentage (16.5%) were employed on a full-time basis. This socio-demographic information is summarised in Table 4.1.

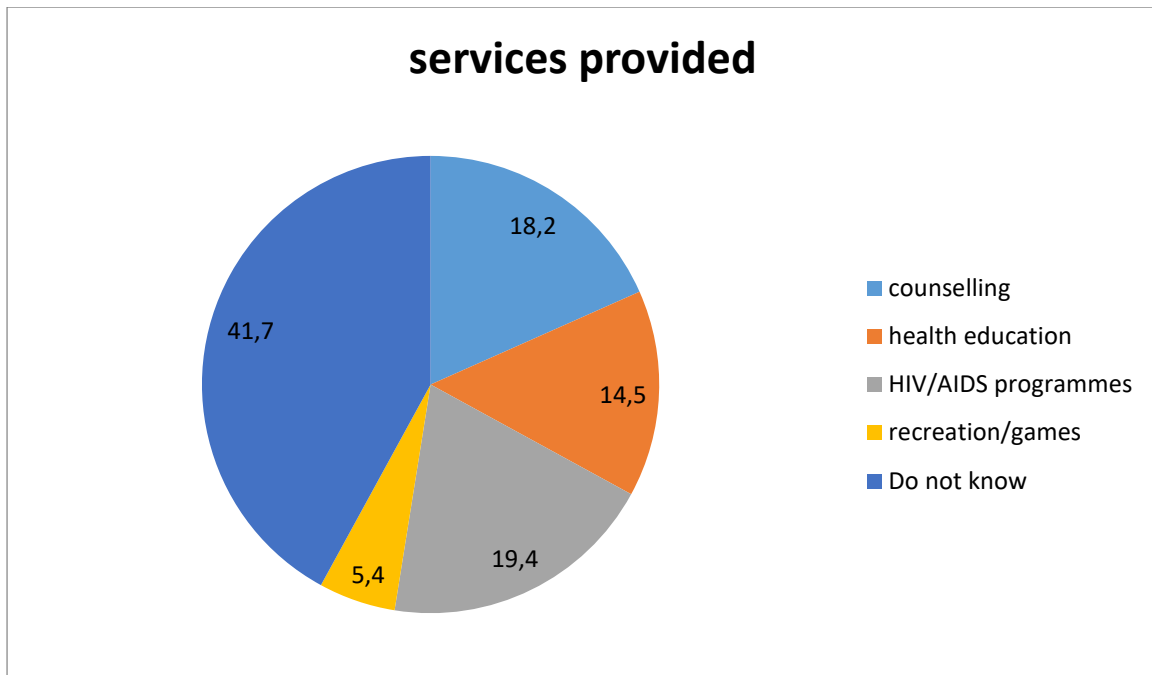


Figure 4.1 Services provided for individuals with disabilities (n=242)

Participants were requested to indicate if they are aware of any services that are provided to individuals with disabilities, and what the types of services are. A large percentage of the participants (41.7%) did not know if any services are provided for them. Almost 20% of the sample indicated their awareness of HIV/AIDS programmes for individuals with a TSCI as indicated in Figure 4.1 below.

Table 4.1 Socio-demographic characteristics of the participants

Characteristics	Total population N (%)	Male n (%)	Female n (%)
Age	(M=33.9, SD=10.3)	(M=35.3, SD=10.4)	(M=32.2,SD=9.9)
< 35 years	141 (58.3)	74 (53.6)	67 (64.4)
≥35 years	101 (41.7)	64 (46.4)	37 (35.5)
Gender	242 (100)	138 (57.0)	104 (43.0)
Marital status			
Never married	131 (54.1)	74 (54.0)	57 (55.3)
Married	56 (23.1)	34 (24.8)	22 (21.4)
Separated/divorced	50 (20.7)	27 (19.7)	23 (22.3)
Widowed	3 (1.2)	2 (1.5)	1 (1.0)
Province			
Western Cape	83 (34.3)	46 (33)	37 (36)
Eastern Cape	39 (16.1)	26 (19)	13 (13)
KZN	58 (24.0)	32 (23)	26 (25)
Gauteng	62 (25.6)	34 (25)	28 (27)
Location			
Urban	194 (81.9)	107 (78.1)	87 (87.0)
Rural	43 (18.1)	30 (21.9)	13 (13.0)
Disability			
Quadriplegia	90 (38)	55 (43.7)	28 (30.4)
Paraplegia	125 (57.3)	65 (51.6)	60 (65.2)
Tetraplegia	10 (4.6)	6 (4.8)	4 (4.3)
Population group			
African	129 (53.3)	65 (47.1)	64 (61.5)
Coloured	58 (24.0)	41 (29.7)	17 (16.3)
White	41 (16.9)	22 (15.9)	19 (18.3)
Indian	8 (3.3)	4 (2.9)	4 (3.8)
Others	5 (2.1)	5 (3.6)	0
Education			
No schooling	12 (5.0)	7 (5.1)	5 (4.8)
Some primary education	16 (6.6)	10 (7.2)	6 (5.8)
Primary education completed	16 (6.6)	10 (7.2)	6 (5.8)
Some secondary education	57 (23.6)	38 (27.5)	19 (18.3)
Secondary education completed	92 (38.0)	46 (33.3)	46 (44.2)
Some tertiary education	27 (11.2)	17 (12.3)	10 (9.6)
Tertiary education completed	22 (9.1)	10 (7.2)	12 (11.5)
Employment status			
Working full time	40 (16.5)	18 (13.0)	22 (21.2)
Working part time	26 (10.7)	16 (11.6)	10 (9.6)
Unemployed	106 (43.8)	59 (42.8)	47 (45.2)
Pensioner	46 (19.0)	31 (22.5)	15 (14.4)
Other	23 (9.5)	14 (10.1)	9 (8.7)

In addition to their awareness of services provided, participants were requested to indicate if they are aware of any peer education with regards to HIV/AIDS for individuals with spinal cord injuries. Almost two-thirds (63.3%) indicated that they are aware of this type of education available and a small percentage (5.8%) indicated that they were not sure as indicated in Figure 4.2.

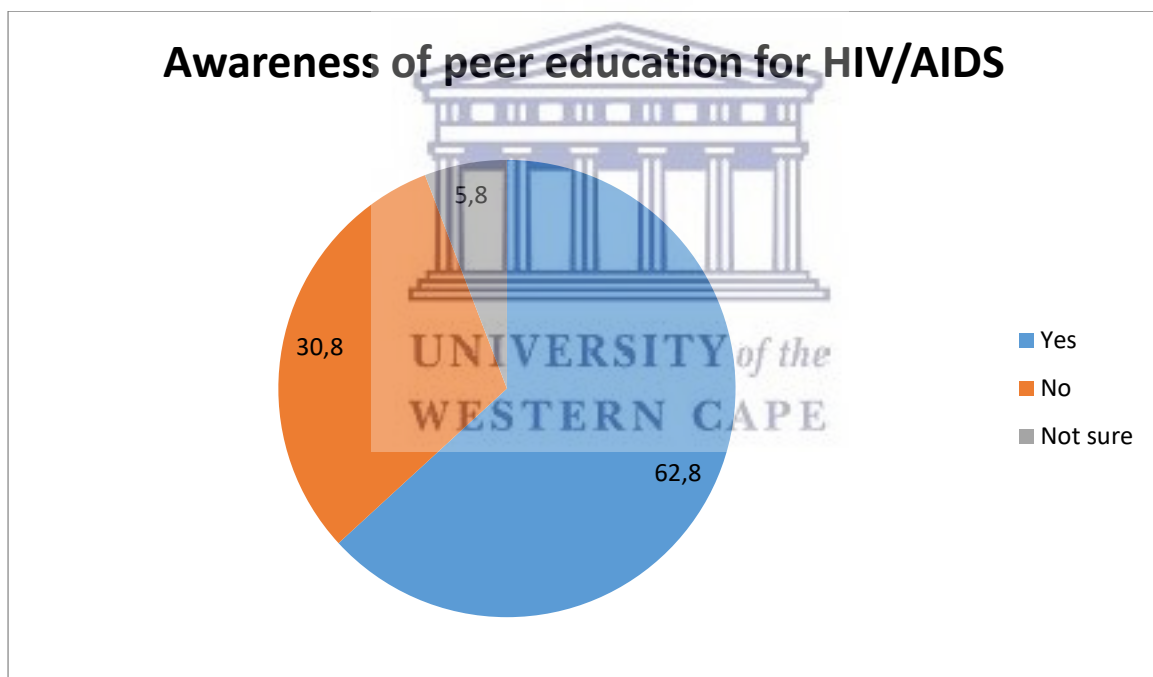


Figure 4.2 Awareness of peer education for HIV/AIDS (n=242)

4.3 PREVALENCE OF SEXUAL RISK BEHAVIOUR

The prevalence of sexual risk behaviour is summarised in Table 4.2. The majority (90.9%) (n = 220) of the participants reported having had sex in their lifetime. A further 71.5% of the participants reported to have been sexually active at the time of the survey. There was no significant difference between males (80.3%) and females (74.7%) reporting to be sexually active at the time of the survey ($p > 0.05$). The number of sexually active participants who reported early sexual intercourse before the age of 15 years old was significantly higher among males (17.6%) than females (9%) ($p < 0.05$, $\chi^2 = 3.58$). A significant higher percentage of males (50.7%) than female (36.5%) reported multiple sexual partners after sustaining a TSCI ($p < 0.05$, $\chi^2 = 4.51$). Almost half (47.5%) of the study sample indicated no condom use with last sexual intercourse. One quarter (24.8%) of the total study sample knew their HIV status with a significant higher percentage of females (31.7%) than males (19.6%) knowing their status ($p < 0.05$, $\chi^2 = 5.39$).

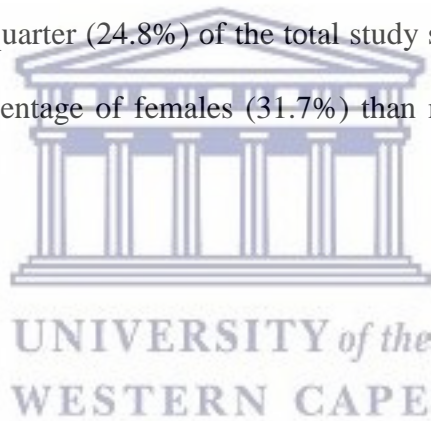


Table 4.2 Prevalence of sexual risk behaviour among the participants


Variable	N	Male (%)	Female (%)	Total (%)	χ^2	p-value
Lifetime Sexual Activity						
Yes	220	92.8	88.5	90.9		
No	22	7.2	11.5	9.1	1.32	.267
					3.582	.05
Early sex debut						
Before 15 years	33	17.6	9.0	14.0		
After 15 years	203	82.4	91.0	86.0		
					3.58	.042
Multiple life partners before TSCI						
One partner	33	17.4	8.7	13.6		
More than one	203	81.2	87.5	83.9		
					4.073	.004
Multiple partners after TSCI						
Yes	108	68.6	53.3	62.4		
No	65	31.4	46.5	37.6		
					5.10	0.078
Condom use last sex						
Yes	115	45.3	51.5	47.9		
No	99	46.7	34.0	41.3		
Missing	26	8.0	14.6	10.8		
Know HIV Status						
Yes	60	19.6	31.7	24.8		
No	70	29.0	28.8	28.9		
Not disclosing	112	51.4	39.4	46.6	5.39	0.047

4.4 MEDIATING (PROTECTIVE FACTORS)

Mediating or protective factors examined in this study includes HIV knowledge, self-efficacy for condom use, self-efficacy to refuse sex and communication skills on sexual related issues. Independent t- test was conducted to compare the mean values of these mediating (protective) factors for HIV prevention for males and females.

No significant difference between the mean values of HIV knowledge for males (M = 12.49, SD = 4.18) and female (M = 12.75, SD = 3.82) were found ($p > 0.05$). Furthermore, no significant difference was found between the mean values of self-efficacy for condom use, self-efficacy to refuse sex and sexual communication for males and females ($p > 0.05$) as indicated and summarized in Table 4.3.

Table 4.3 Gender differences in the mean mediating factors scores for all the participants



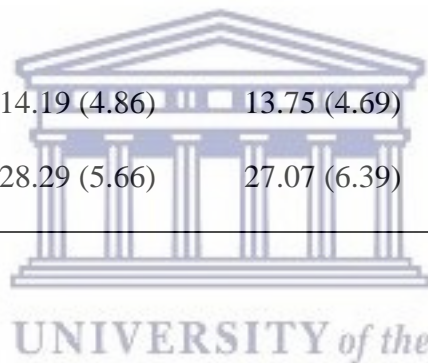
Variable	N	Male M (SD)	Female M (SD)	df	t	p-value
HIV Knowledge	238	12.49 (4.18)	12.75 (3.82)	236	0.49	.624
Self-Efficacy Condom Use	238	18.38 (3.23)	18.62 (3.53)	236	0.55	.581
Self-Efficacy Refuse Sex	241	13.88 (4.99)	13.69 (4.53)	239	0.31	.760
Sexual Communication	234	28.29 (5.62)	27.04 (6.35)	232	1.59	.113

ns= not significant at $p < 0.05$

Independent-samples t-tests were also conducted to test differences in mean scores on mediating factors for sexually active persons with TSCI. As shown in Table 4.4, no significant differences were found on any of the mediating factors outcomes.

Table 4.4 Gender differences in the mean mediating factors scores for sexually active group

Variable	N	Male M (SD)	Female M (SD)	df	t	p-value
HIV Knowledge	216	12.58 (4.06)	12.68 (3.89)	214	0.18	.860
Self-Efficacy Condom Use	217	18.39 (3.28)	18.81 (3.54)	215	0.89	.373
Self-Efficacy Refuse Sex	219	14.19 (4.86)	13.75 (4.69)	217	0.68	.496
Sexual Communication	214	28.29 (5.66)	27.07 (6.39)	212	1.49	.139



Independent-samples t-tests was conducted to compare the mean values of the mediating (protecting) factors for HIV for those that reported having received peer education and those not receiving peer education regarding HIV protection. For HIV knowledge, mean scores indicated that those participants that (M = 13.11, SD = 3.73) had significant higher scores than those who had not received peer education (M = 11.83, SD = 4.41)($p < 0.05$). For use condoms, self-efficacy to refuse sex and sexual communicating mean scores indicated no difference between those reporting peer education ($p < 0.05$).as summarised in Table 4.5.

Table 4.5 Differences in the mean mediating factors scores between participants who received peer education and those who have not

Variable	N	Peer Education M(SD)	No peer education M(SD)	df	t	p-value
HIV Knowledge	223	13.11 (3.73)	11.83 (4.41)	221	2.24	.026
Self-Efficacy Condom Use	223	18.45 (3.44)	18.60 (3.29)	221	0.32	.748
Self-Efficacy Refuse Sex	225	13.86 (5.03)	13.82 (4.16)	223	0.06	.953
Sexual Communication	220	28.01 (5.44)	26.99 (6.21)	218	1.24	.216

4.5 PREDICTORS OF SEXUAL RISK BEHAVIOURS

A logistic regression analysis was performed to assess the factors that were associated with being sexually active among the participants (Table 4.6). All the selected covariates were fitted into the logistic regression model to predict the likelihood of being sexually active among the participants. The *Hosmer-Lemeshow Goodness of Fit Test* indicated support for the model to reliably predict sexual intercourse ($\chi^2 = 11.89$, $p = .156$). As shown in Table 4.6, no variables fitted in the model were statistically significant predictors of reporting being sexually active among the participants.

Table 4.6 Logistic regression predicting likelihood of reporting being sexually active

Variable	B	S.E	Wald	df	p	OR	95% C.I OR
Gender	.45	.49	0.86	1	.353	1.58	0.60-4.11
HIV Knowledge	.02	.06	0.08	1	.773	0.98	0.87-1.11
Self-Efficacy Condom Use	.11	.07	2.38	1	.123	0.89	0.77-1.03
Self-Efficacy Refuse Sex	.07	.05	1.75	1	.185	0.93	0.84-1.03
Sexual Communication	.01	.04	0.00	1	.989	0.99	0.92-1.08

Illustrated in Table 4.7 is the logistic regression to assess the possibility of a number of factors predicting the likelihood of participants reporting sexual activities before and after the age of 15 years. The *Hosmer-Lemeshow Goodness of Fit Test* indicated the model was able to reliably predict early sexual activities ($\chi^2 = 6.03$; $p = .644$). The Wald statistics indicated that gender, self-efficacy in condom use and self-efficacy to refuse sex were statistically significant predictors in the model. Female participants were about 2.53 times (OR = 2.53; 95% CI = 1.03-6.21) less likely to report early sexual experience compared to males. Participants who showed self-efficacy in condom use were about 0.87 times (OR = 0.87; 95% CI = 0.77-0.98) less likely to have an early sexual debut, and participants who showed self-efficacy in refusing sex were also about 1.06 times (OR = 1.06; 95% CI = 1.01-1.19) less likely to have an early sexual debut

Table 4.7 **Logistic regression predicting likelihood of reporting early sexual debut**

Variable	B	S.E	Wald	df	p	OR	95% C.I OR
Gender	.93	.46	4.09	1	.043	2.53	1.03-6.21
HIV Knowledge	.05	.05	1.07	1	.302	1.05	0.96-1.15
Self-Efficacy Condom Use	.14	.06	5.11	1	.024	0.87	0.77-0.98
Self-Efficacy Refuse Sex	.09	.04	4.74	1	.029	1.06	1.01-1.19
Sexual Communication	.02	.04	0.16	1	.691	0.99	0.92-1.06

Table 4.8 shows the results of the logistic regression analysis for predicting condom use at last sex among the study participants. The *Hosmer-Lemeshow Goodness of Fit Test* indicated the model was able to reliably predict early sexual activities ($\chi^2 = 2.22$; $p = .974$). The results indicate that only self-efficacy to refuse sex was a significant predictor of condom use at last sex. Participants who have greater self-efficacy to refuse sex are .91 times more likely to use condoms (OR = .91; 95% CI = .85-.97).

Table 4.8 Logistic regression predicting likelihood of reporting condom use at last sex

Variable	B	S.E	Wald	df	p	OR	95% C.I OR
Gender	.57	.30	3.60	1	.059	.57	.31-1.02
HIV Knowledge	.02	.04	0.24	1	.627	.98	.91-1.06
Self-Efficacy Condom Use	.01	.04	0.09	1	.759	1.01	.93-1.10
Self-Efficacy Refuse Sex	.10	.03	8.03	1	.005	.91	.85-.97
Sexual Communication	.04	.03	2.94	1	.139	1.04	.99-1.09

Table 4.9 shows the results of the logistic regression analysis for predicting lifetime multiple partners among the study participants. The *Hosmer-Lemeshow Goodness of Fit Test* indicated the model was able to reliably predict early sexual activities ($\chi^2 = 9.01$; $p = .341$).

The Wald statistics indicated that only gender was a statistically significant predictor in the model. Male participants were about 2.63 times (OR = 2.63; 95% CI = 1.17-5.91) more likely to report lifetime multiple partners.

Table 4.9 Logistic regression predicting likelihood of reporting lifetime multiple partners

Variable	B	S.E	Wald	df	p	OR	95% C.I OR
Gender	.97	.41	5.41	1	.020	2.63	1.17-5.91
HIV Knowledge	.03	.06	0.19	1	.659	1.03	0.92-1.14
Self-Efficacy Condom Use	.03	.06	0.27	1	.605	0.97	0.87-1.09
Self-Efficacy Refuse Sex	.01	.05	0.01	1	.949	1.00	0.91-1.10
Sexual Communication	.01	.03	0.07	1	.794	0.07	0.93-1.06

4.6 SUMMARY OF THE CHAPTER

The findings from this study highlight the following key messages:

- The majority of participants 76% were single I.e. either never married, separated, divorced or widowed,
- About three quarters 77.9% of the study sample reported being sexually active at the time of the survey. A further 47.9% of the sample indicated condom use at last sexual intercourse.
- Early sexual debut was reported by 13.6% of the sample and 44.6% multiple sexual partners after sustaining a TSCI. Male participants were about 2.63 times (OR = 2.63; 95% CI = 1.17-5.91) more likely to report lifetime multiple partners.
- Although self-efficacy to refuse sex was low and 46.4% of participants reported not using condoms during last sexual intercourse, participants who have greater self-efficacy to refuse sex were .91 times more likely to use condoms (OR = .91; 95% CI = .85-.97).
- Participants reported to having had peer education regarding HIV, had significant higher HIV knowledge scores than those not receiving peer education
- Overall only 24.8% of participants knew their HIV status and females were significantly more likely to know their status than males.

The next chapter will outline the findings of the qualitative components of the study.

CHAPTER 5

EXPLORATION OF SOCIO-CULTURAL ISSUES THAT COULD CONTRIBUTE TO VULNERABILITY TO HIV/AIDS FOR INDIVIDUALS WITH A TSCI

5.1 INTRODUCTION

In this chapter the results of the content analysis of the interviews which attempted to answer the second objective of the study, to explore the socio-cultural issues that might increase individuals with TSCI's vulnerability to HIV/AIDS. Individual interviews were conducted with individuals who participated in the first phase of the study (detailed description of methods used in Chapter 3).

5.2 INDIVIDUAL INTERVIEWS WITH INDIVIDUALS WITH A TSCI

The individual interviews were facilitated by the researcher and a research assistant. Ten (10) participants agreed to participate and included a fairly equal number of males and females as well as quadriplegics and paraplegics. The age of the participants ranged from 21 to 55 years (Mean = 33.8). The demographic information of the participants is summarised in Table 5.1. The interviews took place in a relaxed and convenient setting for the participants.

Table 5.1 Distribution of the Socio-Demographic Characteristics of the Respondents (n=10)

Participants	Gender	Age (Years)	Class of TSCI	Years Since TSCI (Years)	Current work status	Race
P1	Female	36	Paraplegia	5	Unemployed	Black
P2	Male	43	Paraplegia	12	Unemployed	Coloured
P3	Female	34	Paraplegia	1	Unemployed	Black
P4	Male	30	Tetraplegia	13	Unemployed	Coloured
P5	Male	55	Quadriplegia	30	Employed	White
P6	Female	21	Quadriplegia	3	Internship	Black
P7	Female	28	Quadriplegia	6	Internship	Black
P8	Male	23	Paraplegia	8	Internship	Indian
P9	Male	44	Paraplegia	15	Employed	Black
P10	Male	51	Quadriplegia	51	Employed	White

5.2.1 EMERGING THEMES

All the participants were encouraged to feel free to express their views regarding vulnerability to HIV/AIDS as a survivor of a traumatic spinal cord injury.

Overall, four major themes emerged from the analysis. These themes are outlined below:

- Asexuality
- Relationships
- Vulnerability to HIV/AIDS
- Awareness of HIV/AIDS risk and response

Table 5.2 Themes and Sub-Themes

Major Themes	Sub-Themes
Asexuality	Perceptions from others Social disapproval/culture
Relationships	Disconnection Disappointment
Vulnerability to HIV/AIDS	Condom use Myths Abuse Lack of knowledge Other risk-taking behaviour
Awareness of HIV/AIDS risk	Awareness Response

Verbatim quotes will be used to further illustrate the abovementioned themes.

THEME 1: ASEXUALITY

To discuss issues around HIV/AIDS and vulnerability to it as an individual who survived a TSCI, the issue of sexuality is inevitable. The notion of being seen as “asexual” became apparent throughout the interviews. Quotes from the participants confirmed this viewpoint and the notion of being asexual or not being able to have meaningful sexual relationships were highlighted:

“It seems that to me there’s a perception that some of the women who get involved with people with spinal cord injuries have almost resigned the fact or accept the fact that sex will not be an option and so are quite happy to accept other options for satisfaction.” (P5, Male)

“Okay, uhm, usually people have the perception that people with spinal cord injuries can’t be uhm sexually active.” (P4, Male)

“Yeah there is a lot of stigma and stuff out there, like people normally tend to say that guy is paralysed and he can’t have sex, he can’t have children, he can’t do this.” (P2, Male)

Individuals with a TSCI seem to not only be seen as asexual, but they described what is viewed as almost a sense of disapproval from society.

“You are not supposed to have relationships in their eyes, in their minds.” (P1, Female)

“They make big eyes when we have relationships.” (P1, Female)

“You are not supposed to have a boyfriend.” (P1, Female)

Together with this sense of disapproval, cultural influences were also highlighted:

“In our culture... the family won't accept a wheelchair bound person. In the Xhosa culture.” (P1, Female)

These perceptions experienced by members of communities could be due to the lack of knowledge in communities regarding the abilities of individuals with a TSCI:

“A guy will come and ask can you do stuff like this, can you make love, can you have sex, can you do anything like a able person can do?” (P3, Female)

“Why now all of a sudden things must change?” (P1, Female)

“I have been involved in a relationship and when it came to sexual activity I have been told ‘we should not have sex, we can get hurt’ by a girlfriend of mine.” (P10, Male)

Further to the issue of knowledge, it became apparent that individuals with a traumatic spinal cord injury can make use of “alternative methods” to assist with physical sexual relations as illustrated below:

“Although we do not get a ‘durable’ erection, we can use alternative methods such as Viagra, the pump or the injection to help with erection, but most women do not know that you need to be careful when injecting as it can lead to bleeding.” (P10, Male)

THEME 2: RELATIONSHIP DISCONNECTION AND DISAPPOINTMENT

Participants were keenly aware of how their injury influenced their relationships with their partners. Some of these issues were related to their subsequent disability and the end of relationships:

“I broke it off because I could see what he was like when he sees me, he was like he was the one who’s in a wheelchair more than me.” (P3, Female)

“I had my relationship, the one that I had before the accident, it lasted for about a year after the accident.” (P1, Female)

For others a sense of mistrust in their partners’ motivation for staying in the relationship was evident:

“I could not trust them, I did not trust them and I know they did have relationships with other guys. The only reason they kept me around was because of the money, when the money dried up they were gone.” (P2, Male)

“I mean some of them used me for sex, some of them wanted a relationship but then after a couple of weeks it’s like the wheelchair turns them down, like off.” (P2, Male)

A concern on the part of both male and female participants were observed with regard to disappointing their partners:

“Then I’ll be too worried that I won’t be able to do it now, even if I know how to do it. But then I won’t be able to because he’s too worried.” (P3, Female)

“I was definitely afraid of not satisfying them because they had no knowledge about my injury and what’s it all about.” (P2, Male)

A sense of curiosity with regard to their ability to engage in a sexual relationship after the injury was also observed. This participant described his first sexual encounter not as a “relationship” but rather “an activity”:

“My first sexual relationship after accident....actually in rehab, funny enough, it wasn’t a relationship, it was an activity. I requested the opportunity to test my sexuality and I had a willing partner who would agree to participate in the activity.”

(P5, Male)

THEME 3: VULNERABILITY TO HIV/AIDS

It became clear that individuals with a spinal cord injury are vulnerable to contracting HIV in various ways. These included personal risk taking as well as cultural beliefs and myths.

Condom use

Various issues relating to condom use was elicited during the interviews. Some of these issues pointed to a deliberate choice in not using condoms, whereas others pointed to not being prepared for sexual activity. The sense of deliberate “risk-taking” was more evident from the male participants as shown below:

“No, I wanted skin on skin, finish and ‘klaar’.” (P5, Male)

“I have used condoms in sexual relationships but more without than with.” (P5, Male)

“I’ve had sexual relationships without condoms; I’ve used condoms as well.” (P2, Male)

While for others it was more the fear of rejection that motivated them to not use a condom:

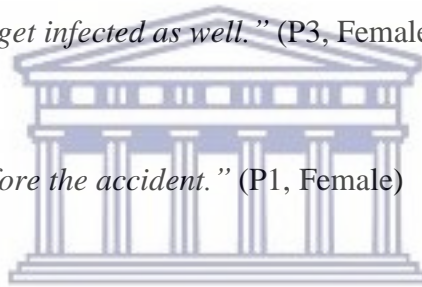
“I am scared that if I ask a girl to use a condom, she will not have sex with me and I do not get a lot of chances, so I rather do without a condom.” (P10, Male)

The risk-taking behaviour shown above, was not as evident from the female participants:

“Yes, I did use protection.” (P6, Female)

“Yes, why not. I could get infected as well.” (P3, Female)

“Yes, always. Even before the accident.” (P1, Female)



An assumption of trust was seen from some of the participants. These assumptions were purely because they knew the partners for a long time and not because they knew their status.

“No, I did not use protection.” And on prompting: *“I knew her for a very long time.”* (P8, Male)

“If you’ve been together for a long time you can continue, I think some people do continue.” (P7, Female)

One participant shared that he did not expect sexual activity and was therefore unprepared, and therefore did not use a condom:

“No, I was not prepared for it, I didn’t know it was going to happen.” (P4, Male)

Another participant, however, clearly stated that she insisted on condom use:

“He should state his reasons why not and then I will probably listen to it but still I would want a condom.” (P3, Female)

“After attending peer support training on HIV, I nowadays use condoms. I was scared when my friend was diagnosed with HIV and we had sex without a condom.” (P10, Male)

Myths

The myths that prevailed in some cultures posed a threat of abuse to individuals with a spinal cord injury and hence a risk of HIV.

“There is this belief that if you sleeping with a disabled person there’s a chance of getting rid of HIV/AIDS, you know.” (P9, Male)

“Some people also think that people with spinal cord injuries are all virgins.” (P10, Male)

“And this whole Satanism thing now, this mutilation thing, they say disabled people make the best muti whenever.”

Abuse

Abuse was highlighted by several participants. They highlighted that abuse occurs for various reasons, but also due to the perception that individuals with a TSCI are desperate for sex as shown below:

“The fact that most people think or thought that you are not supposed to be in a relationship, they tend to abuse you, especially if you are a quiet person and you can’t stand up for yourself. They do a lot. Because they know, maybe they think that you are desperate for sex and there is no one looking for you.” (P1, Female)

Sexual abuse and rape by caretakers or assistants seemed to be common:

“I was once sexually abused by a very good friend who was my caretaker.” (P10, Male)

“I know of the one incident, one of my friends. He left home and went to go stay in X Centre, and he got raped there and he is over 25 years old.” (P2, Male)

In addition, it also seemed common that people tend to not talk about abuse:

“Oh it’s common. I think it’s spoken about less. I think less people with spinal cord injury talk about sexual abuse.” (P5, Male)

“I’ve heard they stay indoors. You will only find through pregnancy or when they get sick then you realise but that person was not safe indoors.” (P1, Female)

Participants highlighted that they are vulnerable as they cannot defend themselves physically:

“We are so vulnerable on this thing (abuse). For us to make it, we need to make sure that we are safe.” (P8, Male)

“I think we are easy target for most people, that’s how we get treated, because you don’t have power to defend yourself if somebody abuses or sexually abuses you...ja, how you going to defend yourself.” (P6, Female)

Lack of knowledge regarding HIV for individuals with a TSCI

It seemed that a large part of the communities in which the participants lived, had no or inadequate knowledge regarding the risk of HIV for individuals with a TSCI.

“No knowledge in our community about spinal cord injury and what that person can do.” (P2, Male)

“They say why do you fear for HIV if you cannot have sex.” (P10, Male)

The lack of knowledge was not only restricted to members in communities, but was also observed from health care professionals:

“The Xhosa people are still, I don’t know, they still not educated about stuff, even the nurses won’t accept the fact that you are pregnant, you are going to be abused everyday by the nurses, when you come to the clinic.” (P1, Female)

This lack of knowledge was not only related to culture, but also disability in itself:

“When I went for HIV testing the sister asked me why I want the test, if I am disabled I should not have sex. When I told her I had sex without protection with someone I do not know, she was shocked.” (P10, Male)

Even partners with a disability displayed this lack of knowledge:

“I think it’s also lack of knowledge, I once dated a disabled guy. He said I won’t use a condom ‘cause I’m paraplegic, I won’t give you babies, I’m not HIV positive. So I was kind of shocked, like how do you know?” (P7, Female)

“I did not think that white girls will have HIV.” (P10, Male)

Other risk taking behaviour

Participants eluded to the fact that some of them also engaged in other risk-taking behaviour such as alcohol and drug use. This behaviour was mostly related to fear:

“I was afraid of not being a man, I wanted to try everything. I actually paid women to have sex with me, that is what I did. And alcohol and drugs played a role.” (P2, Male)

“I usually had alcohol before sex, it made it easier to overcome the psychological barriers.” (P10, Male)

Participants, however, acknowledged that this type of behaviour is risky:

“Irresponsible absolutely, absolutely... it could be alcohol feeds the petrol for lust.” (P5, Male)

“Mmmm...I did yah, maybe use recreational drugs twice while having sex.” (P2, Male)

Other risks

Sexual risks were not the only risks that increased individuals with a TSCI's vulnerability to HIV. Other factors such as bladder and bowel care were shown to pose risks too. These risks were associated with caretakers, as well as bleeding that might occur due to catheters. As some of the participants expressed in their sentiments regarding caretakers:

“Especially when it comes to doing your bowel routine and stuff like that, you never know when they can come with the same gloves from one person....so it's important to make sure that they're using cleaning gloves.”

“Vast risks....catheterising, uhm, putting in suppository, uhm, those.” (P5, Male)

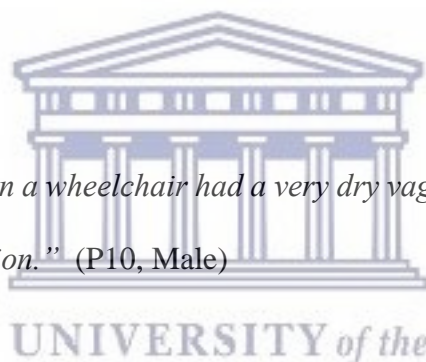
Risks associated with catheters and bleeding were highlighted too:

“I had unprotected sex with my catheter still inside my bladder, it caused some bleeding.” (P10, Male)

Bleeding because of a lack of lubrication was also pointed out by participants:

“So it’s important when you have sex, you use proper lubrication because if there’s not lubrication then the skin can tear and you can have blood to blood transfers.” (P6, Female)

“My girlfriend who is in a wheelchair had a very dry vagina and bleed easily if she did not use lots of lubrication.” (P10, Male)



THEME 5: AWARENESS OF HIV/AIDS RISK AND RESPONSE

Participants were well aware of HIV/AIDS and the risks that they face on the same level that able-bodied individuals do:

“People with spinal cord injuries must be aware of HIV/AIDS. Just as much, no difference.” (P5, Male)

“If I might not use a condom, I don’t know what’s going on with my partner, then definitely I’m at risk.” (P1, Female)

“Up until I attended a HIV course delivered by PWD, I have had many sexual relationships with women of different races, but after going for testing a few years ago I do not do this anymore.” (P10, Male)

The participant further eluded to the fact that education and awareness is needed for people in wheelchairs:

“We need to educate others in wheelchairs because they are not included in normal awareness campaigns.” (P10, Male)

Despite their keen awareness of their risk of contracting HIV/AIDS, their actions were contradictory to this awareness and they seemed to knowingly place themselves at risk:

“I’ve been in danger of being infected with HIV. Before my accident I use to be like, uhm, I slept around a lot. After my accident the same thing, about a year after that I did the same thing.” (P2, Male)

“I have placed myself at risk to be infected with HIV/AIDS, yah definitely. I never, I haven’t asked a person that I’m with whether they have taken an HIV and AIDS test but it’s always on my mind.” (P5, Male)

When participants were prompted with regard to HIV testing it was evident that some were tested only as part of the routine when admitted to hospital:

“Yes, they done it in hospital.” (P3, Female)

“Just after the accident, before the operation.” (P1, Female)

Others seemed to realise the importance of testing more, and do it more regularly:

“Six months ago.” (P2, Male)

“But I, myself, on the 1st of December every year, I go for an HIV test, every year just because its World Aids Day and I have a test.....every 365 days I know what my status is.” (P5, Male)

It was also pointed out that clinics are not accessible for individuals in wheelchairs and that the attitudes of staff were also not encouraging:

“Test centres and clinics are not accessible, and nurses look at you strangely when you get tested, but I do go for testing every year now and tell them that we can have sex too.” (P10, Male)

5.3 SUMMARY OF THE CHAPTER

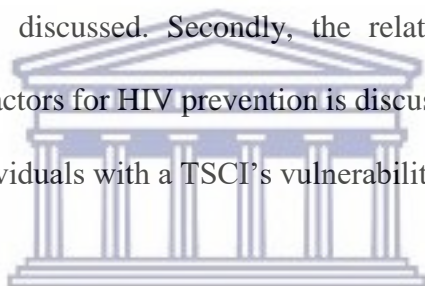
The views of individuals who have sustained a traumatic spinal cord injury regarding their vulnerability to HIV/AIDS were presented in this chapter. The results clearly showed that individuals are exposed to risk in the same way as able-bodied persons because of risk-taking behaviour such as inconsistent condom use, and alcohol and drug use prior to sexual intercourse. In addition, their vulnerability because of their subsequent disability after the traumatic spinal cord injury, posed additional risk such as abuse, and subjection to myths and cultural beliefs. These themes presented in this chapter will be discussed in detail and incorporated with the findings of the quantitative data and compared with the salient literature.

CHAPTER SIX

DISCUSSION

6.1 INTRODUCTION

The main aim of this study was to examine the factors that could contribute to the risk and vulnerability to HIV/AIDS among individuals with a TSCI in South Africa. This chapter thus provides an integrated discussion of the results presented in the preceding two chapters. Firstly, the prevalence of sexual risk behaviour such as sexual debut, the number of partners and the consistency of condom use, is discussed. In addition, the mediating factors for HIV reduction, including but not limited to HIV-related knowledge, sex communication skills, self-efficacy, and sex negotiation skills is discussed. Secondly, the relationship between sexual risk behaviour and the mediating factors for HIV prevention is discussed. Lastly, the socio-cultural issues that might increase individuals with a TSCI's vulnerability to HIV/AIDS are discussed.

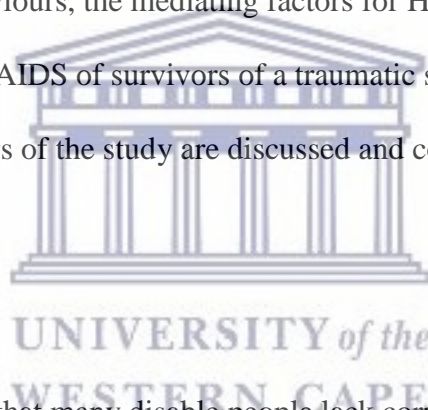


6.2 BEHAVIOURAL FACTORS THAT COULD CONTRIBUTE TO RISK AND VULNERABILITY TO HIV INFECTION AMONG INDIVIDUALS WITH A TRAUMATIC SPINAL CORD INJURY

It is well-established that the behavioural risk factors for HIV associated with sexual activity are exactly the same for the general population and those with disabilities (Groce, 2005). Groce (2005) emphasized that epidemiological data are needed for individuals with disability in general and distinct disability groups as the issue of the impact of the HIV/AIDS epidemic on these individuals are significant and timely. Shisana et al. (2009) pointed out that the prevalence of HIV/AIDS among those with disabilities is as high as those without disabilities.

In South Africa, the vulnerability of people with disabilities to HIV and the need to integrate rehabilitation services into HIV chronic care have been acknowledged in both the South African NSP and the South African Framework and Strategy 2015-2020 on disability and rehabilitation services.

As evident from the literature reviewed in chapter 2, issues related to sexuality and disability and specifically sexuality and individuals with a spinal cord injury has been addressed but limited or no research is available on the HIV/AIDS issues individuals with a traumatic spinal cord injury face and the information they receive on prevention. This study is the first to report on the sexual risk behaviours, the mediating factors for HIV reduction and the socio-cultural issues related to HIV/AIDS of survivors of a traumatic spinal cord injury in South Africa. The significant findings of the study are discussed and compared with salient literature.;



Eide et al. (2011) highlighted that many disable people lack correct information about HIV prevention. In this study however, 63.3% of the participants indicated that they were aware of peer education for HIV/AIDS for individuals with a TSCI. Although this is encouraging, more should be done to ensure that the significant proportion of individuals not aware of these services in their communities, should be made aware. This type of education would prove to be extremely valuable in the prevention efforts for survivors of TSCI as Rohleder et al. (2009) highlighted that appropriate information on HIV for disabled people in general may not be in accessible formats. Who should however be responsible for raising awareness with regards to peer education for HIV/AIDS for survivors of a traumatic spinal cord injury? Kreuter et al. (2011) pointed out that for spinal cord injury rehabilitation to be regarded as

successful, a holistic approach is needed and all the individual's circumstances, including sexuality and or risk of sexual-related diseases should be incorporated. It therefore seems appropriate that raising awareness of peer-education should start while patients are undergoing rehabilitation.

Researchers have made it clear that individuals with a spinal cord injury remain sexual beings and that they can indeed continue to lead sexually satisfying lives (Ostrander, 2009). This is also evident in this study as 71.5% of the participants reported being sexually active at the time of the survey. Of concern however is the high number of participants both males and females, that reported multiple sexual partners since their injury. Because of these casual relationships, these individuals have an increased chance for sexual health problems and risks. Coupled with that is the lack of condom use with their last sexual encounter for both males (46.7%) and females (34.0%). The WHO acknowledged that unsafe sex (sexual intercourse without a condom) is the second most salient risk factor for disease, disability, or death in the poorest communities and the ninth in developed countries (WHO, 2002a). When these risky behaviours shown above are viewed in the context of only 24.8% of the participants knowing their HIV status, alarms with regards to the vulnerability of this group to HIV is raised. This is consistent with the view of Mulindwa (2003) that the behavioural risk factors for HIV associated with sexual activity in this group is exactly the same as for the general population.

Researchers have indicated that the behavioural risk factors for HIV associated with sexual activity are exactly the same for the general population and those with disabilities (Mulindwa, 2003). Efforts to increase the levels of knowledge with regards to HIV should be sharpen and

increased for this group. Research in various parts of the world suggests that sufficient knowledge regarding HIV is a necessary first step, though inadequate in the prevention of the disease (Wong, et al., 2008). At a closer look at the levels of knowledge of HIV, the levels are not particularly high for both males (mean of 12.49, where maximum score is 18) and females (mean of 12.57 where maximum score is 18). This is in comparison with other researchers that pointed out that South Africa and other Southern African countries report low levels of HIV/AIDS knowledge (Wazakili, et al., 2006; Yousafzai et al., 2004). Rohleder et al. (2010) pointed out that DPOs are aware of the fact that people with disabilities are at risk of HIV but no published research is available on the role of these organisations in HIV prevention. As organisations for people with disabilities provide services and advocate on behalf of people with disabilities, they recognise the importance of providing HIV prevention education. Phillips and Malcolm (2006) however asserts that the biggest obstacle to behaviour change is socially supported beliefs and that knowledge should be imparted to the entire at-risk group and larger communities in which the group is embedded. The important role that peer education plays are very evident in this study as those who have received peer education with regards to HIV had significantly higher HIV-knowledge scores than those who have not received peer education. As pointed out earlier in this discussion, peer education should therefore start early in the rehabilitation of individuals with a traumatic spinal cord injury as it is clearly of huge benefit in the fight against HIV/AIDS.

Understanding the determinants of sexual behaviour (e.g. self-efficacy, knowledge etc.) that facilitate or inhibit risky sexual behaviour is critical for developing interventions that decrease opportunities to engage in risk-taking sexual behaviour. In addition, it also substantially enhances the resoluteness of health care providers to identify and offer support for people at risk of HIV infection (Kirby, 2007).

Literature highlights the salient role of self-efficacy in human behaviour. It is clear that participants in this study can significantly improve their self-efficacy in terms of condom use and to refuse sex. Females scored lower than males with regards to their ability to refuse sex. Efforts to improve females' ability to refuse sex should be made. Therefore, in addition to education, efforts should be made to increase individuals' self-efficacy for both condom use and to refuse sex for both genders as literature clearly showed that both males and females with a physical disability are vulnerable and could be exposed to abuse.

6.3 SOCIO-CULTURAL ISSUES THAT INCREASES INDIVIDUALS WITH A TSCI'S VULNERABILITY TO HIV/AIDS

Kreuter et al. (2013) showed that individuals continue to be sexually active after sustaining a spinal cord injury, and that these individuals view this as an important part of their lives. However, the notion of being seen as "asexual" was very evident in this study: "*Okay, uhm, usually people have the perception that people with spinal cord injuries can't be uhm sexually active*". Pebdani, Johnson and Amtmann (2014) is in agreement and stated that those with disabilities are commonly seen as being asexual or sexually innocent. Esmail et al. (2010) also stated that the sexual lives of people with disabilities have conventionally been either avoided or viewed as unthinkable and therefore has so far been a difficult topic to address. These researchers further claim that this idea might also stem from the general public's failure to reconcile the notion of physical disability and sexual relations. Tepper (2000) stated that sex is often seen as a privilege of single, heterosexual, non-disabled persons.

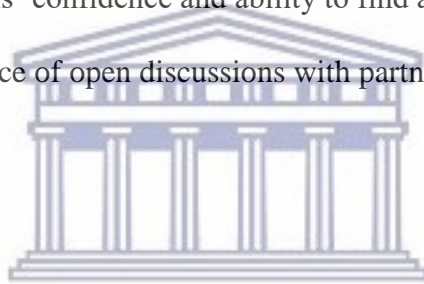
In addition to individuals being seen as asexual, negative attitudes or disapproval from members of the society in terms of being sexually active as a person with disability was also experienced: *“You are not supposed to have relationships in their eyes, in their minds.”* This type of attitude from community members could possibly be due to lack of knowledge with regards to disability and sexuality. However, when educated healthcare professionals display the same kind of ignorance, it could be seen as a cause of concern. Pebdani et al. (2014) made it clear that when healthcare professionals and service providers display negative attitudes towards sex and disability it can have dire consequences. Some of these consequences include issues such as the topic of sex not being discussed which could result in the omission of education and counseling with regards to sexuality and HIV/AIDS prevention. Fischer et al. (2002) also agreed that if more intervention of sexual health after a spinal cord injury is done, it can all lead to very positive effects for those with the subsequent disability.



The lack of knowledge from health care professionals with regards to sexuality and disability is a great concern *“The Xhosa people are still, I don’t know, they still not educated about stuff, even the nurses won’t accept the fact that you are pregnant, you are going to be abused everyday by the nurses, when you come to the clinic.”* Mall and Swartz (2012) noted that healthcare professionals could be seen as complicit in not only blocking people with disabilities their rights to sexuality but also in continuing the myths about asexuality for this group. However, the magnitude of the HIV epidemic and the increased rates of sexual violence against people with disabilities in South Africa compel these healthcare professionals to begin to think critically and carefully about the role they have to play in the area of sexuality of people with disabilities. Kreuter et al. (2013) stated that a crucial issue is that all healthcare professionals should have sufficient knowledge about sexual functioning after spinal cord injuries and therefore feel comfortable raising the issue of sexuality to allow

the patients opportunities to discuss this topic. It is therefore important that rehabilitation efforts should address this important aspect of the patient's life.

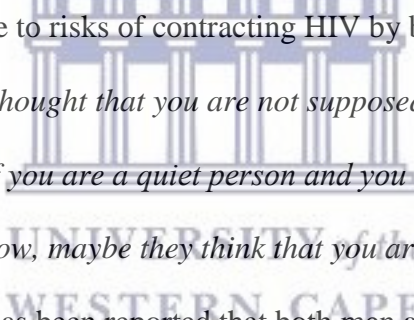
In exploring the concepts of sexuality and disability Esmail et al. (2010) concluded that those with a visible physical disability face more social limitations and stigma of being asexual. In this study participants highlighted in this study as they indicated that issues such as being in a wheelchair influenced their relationships with their partners: *"I broke it off because I could see what he was like when he sees me, he was like he was the one who's in a wheelchair more than me."* Esmail et al. (2010) therefore noted that issues such as highlighted above will have a definite impact on individuals' confidence and ability to find a partner. Kreuter et al. (2011) however stressed the importance of open discussions with partners to share their feelings, anxieties and fears.



The vulnerability to contracting HIV of individuals with a traumatic spinal cord injury was evident in this study as personal risk taking was clear, more from males than females. Issues related to increased risk due to deliberate unprotected sex is a great area of concern: *"I have used condoms in sexual relationships but more without than with."* and *"No, I wanted skin on skin, finish and 'klaar'."* On the other hand, fear of being rejected was the motivation for some to not use a condom: *"I am scared that if I ask a girl to use a condom, she will not have sex with me and I do not get a lot of chances, so I rather do without a condom."* It is therefore clear that whatever the reasons for engaging in unprotected sex, increased efforts should be made include people with spinal cord injuries in HIV prevention programmes. Rohleder et al. (2010) argued that the combination of being assumed to be not at risk with the probability of increased risk is a cause of concern. Eide et al. (2011) also stated that people

with disabilities often lack the correct information and knowledge about HIV/AIDS prevention.

A worrying trend in the South African context is the myths that prevails in some cultures that pose a threat of sexual abuse and therefore the risk of HIV for individuals with a traumatic spinal cord injury: *“There is this belief that if you sleeping with a disabled person there’s a chance of getting rid of HIV/AIDS, you know.”* Groce (2005) added that these types of myths add to the risk that people with disabilities face. This is also in conjunction with the myth that people with disabilities are asexual and therefore virgins.



Participants increased exposure to risks of contracting HIV by being sexually abuse: *“The fact that most people think or thought that you are not supposed to be in a relationship, they tend to abuse you, especially if you are a quiet person and you can’t stand up for yourself. They do a lot. Because they know, maybe they think that you are desperate for sex and there is no one looking for you.”* It has been reported that both men and women with a disability are also very vulnerable and are as much as three times more likely to be raped that those without a disability (Groce, 2005). This author further pointed out that men and boys with disabilities face the same challenges of rape and sexual abuse as their female counterparts.

6.4 SUMMARY OF THE CHAPTER

It is clear from the discussion above that individuals with a traumatic spinal cord injury is vulnerable to the risks of HIV infection. In addition this discussion highlighted that there are cultural issues that increase the vulnerability of individuals with a TSCI to HIV in South

Africa. Concerted efforts should thus be made to protect this vulnerable group of the population by means of empowerment, improving HIV-related knowledge, addressing negative attitudes from healthcare professionals and including people with disabilities in HIV prevention education programmes.



CHAPTER SEVEN

CONCLUSION, RECOMMENDATIONS

7.1 INTRODUCCION

The chapter provides a conclusion to the overall study and highlights the study limitations and provides recommendations for future research.

7.2 CONCLUSION

The combined method of quantitative and qualitative research was found to be most effective to understand and examine the factors that could contribute to the risk and vulnerability to HIV/AIDS among individuals with a traumatic spinal cord injury in South Africa. The qualitative exploration provided depth to this study which would not have been possible by doing a comprehensive quantitative study only. Any limitations that might have presented regarding the quantitative survey were counteracted by the in-depth sharing of experiences in the individual interviews.

This study contributed to the body of knowledge pertaining to sexual health and reproductive health and the vulnerability to HIV/AIDS of individuals with a traumatic spinal cord injury in South Africa as no study was found focusing specifically on this distinct disability group. It is anticipated that the findings of this study could influence those individuals involved in rehabilitation, health promotion, and peer education of individuals with a traumatic spinal cord injury to use ethical, creative and persuasive methods that have a holistic focus. In this manner, promotion campaigns could incorporate as many factors and role-players when appropriate, so that sexual health promotion and HIV-prevention is placed within the larger context of general health promotion. Furthermore, the study could influence the evaluation and planning of health

care policy which in turn would develop health care decision-making that influences the provision of services for improving the quality of life of people with disabilities in general and those with a traumatic spinal cord injury specifically in South Africa.

In conclusion, it is recommended that in the era of the HIV/AIDS pandemic, that comprehensive team-based research be undertaken to investigate the complexity of sexual health and decision-making among people with disabilities and those surviving a traumatic spinal cord injury.

7.3 LIMITATIONS

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

- Data used to report the contribution of mediating factors to sexual risk behaviour were analysed cross-sectionally, thereby limiting the ability to make causal inferences.
- Data were collected through self-reported measures; this is open to desirability bias where participants either over-estimate or under-estimate their true sexual behaviour.
- Participation bias: The researcher acknowledges that participation bias could have influenced the results of this study. Participation bias refers to the various motivations for participating in a study. In this study, participation may have been influenced by a degree of curiosity, given the nature of the topic.
- The sample for this study was non-representative and therefore the results of the study are an indication of the sub-samples in the different provinces but cannot be generalized for all individuals with traumatic spinal cord injuries in South Africa.

7.4 RECOMMENDATIONS

In South Africa the major structure used in the fight against HIV/AIDS/TB is the NSP, it is thus just fitting to align my recommendations with the goals set in the policy.

- ***Increase the priority placed on primary prevention:*** In order to provide access to prevention services to people with disabilities those implementing health care and providing education should be trained on how to accommodate people with disabilities. Health care services should also undergo an audit regarding disability to assess all levels of accessibility of services for people with diverse types of disabilities The inclusion of people with disabilities within this process is crucial.
- ***To scale up comprehensive sexuality education and sexual and reproductive health services:*** Educators of learners with disabilities often lack the skills and materials to provide comprehensive sexuality education to a diverse set of learners in formats that are accessible. These efforts need to include all educational institutions servicing learners with disabilities (inclusive, full-service and special schools) and reach out to organisations of or for people with disabilities. Provision of accessible comprehensive sexuality education material will assist and improve the skills, resources and abilities of educators who teach learners with disabilities. This approach has to be integrated in a whole people and community centred approach to leverage peer support as well as gain support from the relevant communities and service providers.



- ***Multi-sectorality and integration of care:*** Vulnerability and exclusion of people with disabilities as well as the negligence of rehabilitation in the care of the three diseases including co-morbidity of Non communicable diseases (NCD's) are linked to broader social and structural aspects in South Africa. Therefore, all sectors have to make efforts to integrate persons with disabilities into HIV/TB/STI prevention and treatment programmes or services. Similarly, only a multi-disciplinary approach will ensure that health professionals (health and social) and community representatives collaborate to provide an integrated care service that mitigates the impact of the three diseases.
- ***People-centered:*** People with disabilities as well as those living with HIV, TB or STIs, and their households must play a central role in creating awareness with regards to addressing specific needs. The profiling of communities should be undertaken to develop a clearer, more detailed understanding of the local contextual drivers of the epidemics, the individual and community resources and strengths, and the location of available and needed services. This “profiling” needs to include disability indicators to identify people with disabilities as well as their risk factors and needed services
- ***Scale up high-impact interventions:*** High-impact prevention and treatment interventions as well as multi-sector strategies are necessary to address the social and structural drivers of the epidemics. High-impact interventions (such as PrEP, condom distribution, circumcision, ART-roll, PMTCT and comprehensive sexuality education) need to be made available to people with disabilities. In addition, disability

specific interventions need to be evaluated with regards to their impact on risk reduction and improvement of quality of life. This is needed to determine what works and identify which interventions can be up-scaled for impact.

- ***Use granular data for programme design and targeting:*** Using surveillance and other sources of data to understand where new infections are occurring, who is becoming infected and by whom is very important. This data needs to include disability indicators to inform the design and delivery of prevention interventions to ensure that programmes target people with disabilities. This requires disaggregation of data via age, race, gender, and disability. Existing data collection tools, such as Road to Health cards, must be fully leveraged and include these indicators.



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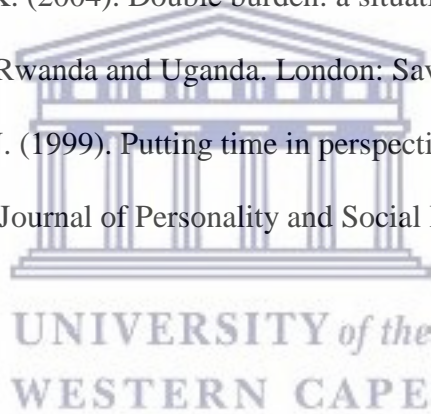
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UNIVERSITY of the
WESTERN CAPE

OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT

5 December 2013

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 J Lloyd (SRES)

Research Project: Behavioural and protective factors contributing to the risk and vulnerability to HIV/AIDS among individuals with spinal cord injuries in South Africa.

Registration no: 13/10/29

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*



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PARTICIPANT INFORMATION SHEET

Project Title: "Risk and vulnerability to HIV/AIDS among individuals with spinal cord injuries in South Africa.

What is this study about?

This is a research project being conducted by Jacobus Lloyd at the University of the Western Cape. The main aim of this project is to examine the factors that could contribute to the risk and vulnerability to HIV/AIDS among individuals who sustained and survived spinal cord injuries in South Africa. I would also like to find out how you experience or perceive your decision-making in relation to engagement in safe or unsafe sexual practices.

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

We will ask you to complete a survey regarding your knowledge of HIV/AIDS; sexual activity; your quality of life; your independence; your communication and negotiation skills in terms of sexuality and your ability to refuse sex; quality of life and your functional status. In addition we will ask you to share your views on your experiences and or perceptions of your decision-making in relation to your engagement in safe or unsafe sexual practices.

Would my participation in this study be kept confidential?

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

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

What are the risks of this research?

There are no known risks associated with participating in this research project. However, counselling services will be available to you if you have had past sexual traumatic experiences.

What are the benefits of this research?

This research project will provide essential knowledge on the sexual health promotion needs of individuals who have sustained a traumatic spinal cord injury. This may then assist with the development of a systematic structure of care for patients like you from the time of sustaining the injury up until the time that you take your full place in society again. Furthermore this will be evidence to increase the awareness of individuals with traumatic spinal cord injuries as a high-risk group vulnerable to HIV/AIDS.

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

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

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

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

What if I have questions?

This research is being conducted by Jacobus Lloyd of the SRES Department, University of the Western Cape. If you have any questions about the research study itself, please contact me at: Department of SRES, University of the Western Cape, Private Bag X17, Bellville 7535, South Africa or 0729082908, email: reabledjac@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: Dr S. Basset

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.



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INLIGTING STUK

Project Title: Risk and vulnerability to HIV/AIDS among individuals with spinal cord injuries in South Africa.

Wat behels hierdie studie?

Hierdie is a navorsings project gelei deur Jacobus Lloyd van die Universiteit van Wes Kaapland. Die hoofdoel van hierdie projek is om vas te stel watter faktore bydra tot die risiko en blootstelling aan HIV/VIGS vir persone wat 'n spinal koord besering oorleef het in Suid Afrika. Ons wil ook graag vasstel wat jou ervaring of persepsie is oor jou besluitneming in verband met jou deelname in seks.

Wat sal van my verwag word as ek instem om deel te neem?

Ons jou graag vra om 'n vrae lys in te vul wat handel oor jou kennis van HIV/VIGS; jou seksuele aktiwiteite, jou lewens kwaliteit, jou vermoë om te kommunikeer oor seks, jou vermoë om seks to weier, en jou onafhanklikheid. Ons wil jou ook vra om jou ervaringe of persepsies oor jou besluitneming in verband met seksuele aktiwiteit met ons te deel.

Sal my deelname vertroulik gehou word?

Ons sal alles in ons vermoë doen om te verseker dat u persoonlike inligting vertroulik bly. Om jou te beskerm, sal jou persoonlike inligting 'n kode kry. Alle inligting wat jy ons gee sal streng vertroulik gehou word. Inligting sal op 'n rekenaar gestoor word wat beskerm is deurdat toegang slegs gekry kan word deur 'n geheime kode. Wanneer ons 'n verslag skryf sal ons jou identiteit ook so ver as moontlik beskerm.

Wat is die risiko van hierdie navorsings projek?

Daar is geen bekende risiko wat verband hou met hierdie projek nie.

Wat is die voordele van hierdie navorsing?

Hierdie navorsing sal inligting verskaf oor die faktore wat bydra tot die blootstelling aan HIV/VIGS vir persone wat 'n spinal koord besering oorleef het. Dit sal dan help om 'n sistematiese stelsel van versorging vir pasiente soos jy vanaf die tyd van besering totdat jy weer jou plek kan volstaan in die gemeenskap. Die kennis oor die gesondheids gewoontes en risiko sal die bewustheid verskerp sodat individue met spinal koord beserings kan dopgehou word vir die risiko faktore.

Moet ek deelneem en mag ek my deelname enige tyd stop?

Jou deelname is heeltemal vrywillig. Jy kan kies om glad nie deel te neem nie. As jy wel besluit om deel te neem kan jy jou deelname enige tyd stop sonder dat dit jou enigsins sal benadeel.

Is daar enige hulp beskikbaar indien ek negatief beïnvloed sou word as ek deel neem aan die studie?

Jy sal verwys word na die toepaslike gesondheidsorg personeel indien die noodheid vir verwysing sou opduik.

Wat as ek vra het?

Hierdie navorsing word gelei deur Jacobus SRES Department by die Universiteit van Wes Kaapland. As u enige vra oor die navorsing het, kan u my kontak by: SRES Departement by die Universiteit van Wes Kaapland, Privaatsak X17, Bellville 7535, Suid Afrika of 0729082908, e-pos: reabledjac@gmail.com

As jy enige vra het oor die studie en jou regte as deelnemer of as jy enige probleme ondervind as deel van die navorsing, kontak asseblief:

Hoof van Departement: Dr S Basset

Dekaan van die Fakulteit Community and Health Sciences: Prof J. Frantz

Universiteit van Wes Kaapland
Privaat Sak X17
Bellville 7535



Hierdie navorsing is goed gekeur deur die Universiteit van Wes Kaapland se Senaat Navorsings en Etiese Komitee.



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INKCUKACHA ZOMTHATHI NXAXHEBA

Project Title: Risk and vulnerability to HIV/AIDS among individuals with spinal cord injuries in South Africa.

Lungantoni oluphando?

Oluphando lwenziwe lwalungiswa ngu Jacobus Lloyd kwi Yunivesithi yase Ntshona Koloni. Injongo yoluphando kukufumanisa ukuba bangaphi abantu abaphila kakuhle emva kokusuleleka yintsholongwane HIV/AIDS nokulimala ngomnqonqo kwiphondo lwe Ntshona koloni, eMzantsi Afrika. Singathanda nokwazi kananjalo ngezizigqibo abazithathayo kwimeko zezesondo ukuba uyazikhusela na okanye hayi.

Ndizakubuzwa imibuzo enjani uba ndiyavuma ukuthatha inxaxheba?

Singathanda ukuba uphendule imibuzo malunga nolwazi lwakho nge HIV/AIDS, ukuthabatha inxaxheba kwezesondo, indlela ophila ngayo, ukuzimela kwakho, indlela onxulumana ngayo nababnye abantu malunga nezesondo, neqanaba lempilo yakho. Ukongeza singathanda ukuba usibalisele ngendlela ocingangayo kwisizigqibo kwezidibene nezesondo ukuba uyazikhusela na okanye hayi.

Ukuthatha kwam inxaxheba koluphando luzogcinwa luyi mfihlo na?

Sizakwenza konke okusemandleni ukukhusela inkcukacha zakho. Ukuncedisana noku, igama lakho nezinye inkcukacha ezibalulekileyo ziyakunikwa amagama afihlakeleyo. Zonke inkcukacha ngalengcombolo iyakubaselugcinenwi oluyimfihlo. Lengcombolo iyakugcinwa kwii compiyutha ezinezazisi esiyimfihlo nakwezinye izigcini. Okongokuba siyabhala ngoluphando siyaqinisekisa ukuba sakulikhusela igama lakho. Ukuba kuyenzeka sibhale isiqendu malunga noluphando, iinkcukacha zakho ziyakukhuselwa kangangoko.

Bungayintoni ubungozi boluphando?

Asizange sadibana nobungozi kuphando oluloluhlobo. Ukuba uthe kanti kwixa elagqithayo wakhe wahlukumezeka ngakwezesondo, abantu abaqeqeshelwe ukuthetha nokunceda bayobe bekhona belinde ukunceda.

Yintoni endizakuyizuzisa ngoluphando?

Oluphando luzakubaluncedo ekutheni abantu babenolwazi ngokuthi kwenzeke ngokwezesondo xa uthe wonzakala umnqonqo nezinto ezenziwa kokulimala. Oku kunanceda nasekubeni kubekho indlela yokuhlela nokucwangcisa indlela yokunakekela abantu abafana nawe, usukela ngexesha lomonzakalo ukuya kwixesha lokuphila ude ubuyele eluntwini. Ukongeza, oku kukuyoba bubungqina bokuphuhlisa ulwazi kwabo bathe bahlikumezeka ngomonzakalo womnqonqo ngokobungozi obukhulu kwi HIV/AIDS.

Kunyanzelekile ndibekoluphando kwaye ndingayeka nanini na ndifuna?

Ukuthatha inxaxheba koluphando kungokuthanda kwakho. Ungakhetha ukungathathi nxaxheba xa ufuna. Ukuba ugqibe ekubeni uthathe inxaxheba koluphando, ungayeka nanini na ufuna. Noba awuthathi inxaxheba okanye koluphando okanye uyeke nje esithubeni awusoze wabhencwa igama lakho okanye amalungelo nemfanelo zakho.

Lukhona uncedo endizolufumana uba ngaba oluphando lundichaphazela ngendlela engalunganga?

Uyakukuthunyelwa kwicandelo lwempilo lwezoluleko ukuba ngaba kukho imfuneko yoko ngelixa uthatha inxaxheba koluphando.

Ndingenza njani xa ndinemibuzo ngoluphando?

Oluphando lwenziwa ngu Jacobus Lloyd, kwicandelo SRES Yunivesithi yaseNtsona Koloni [Ukuba ungaba nemibuzo ngoluphando, unganxulumana nam ku: Department of SRES, University of the Western Cape, Private Bag X17, Bellville 7535, South Africa or 0729082908, email: reabledjac@gmail.com](mailto:reabledjac@gmail.com)

Ukuba unemibuzo malunga noluphando njengomthathi nxaxheba okanye ufuna ukukhalaza ngengxaki othe wazifumana ezinxulumene noluphando, nceda unxulumane no:

Head of Department: Dr S. Basset

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

University of the Western Cape
Private Bag X17
Bellville 7535

Oluphando luququzelwe ngokwasemthethweni ligqiza lophando ne komiti yezo..ethics kwi Yunivesithi yase Ntshona Koloni.



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CONSENT FORM

Title of Research Project: Risk and vulnerability to HIV/AIDS among individuals with spinal cord injuries in South Africa.

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 also give permission for our interview to be audio-recorded.

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: Jacobus Lloyd

University of the Western Cape

Private Bag X17, Belville 7535

Telephone: (021)959-2542

Cell: +27829921549

Fax: (021)959-1217

Email: reabledjac@gmail.com



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TOESTEMMINGSVORM

Titel van Navorsingsprojek: "Risk and vulnerability to HIV/AIDS among individuals with spinal cord injuries in South Africa."

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

Naam van deelnemer: _____

Getuie: _____

Handtekening van deelnemer: _____

Datum: _____



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WESTERN CAPE

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

Studie Koördineerder: Jacobus Lloyd

Universiteit van Wes-Kaapland

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Iphepha Mvume Lomthathi nxaxheba

Title of Research Project: Risk and vulnerability to HIV/AIDS among individuals with spinal cord injuries in South Africa.

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

Igama lomthathi nxaxheba:

Tyikitya:.....

Usuku:

Ukuba unombuzo nxibilelana:

Jacobus Lloyd

University of the Western Cape

Private Bag X17, Belville 7535

Telephone: (021)959-2542

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RISK OF HIV/AIDS QUESTIONNAIRE

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



INSTRUCTIONS

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

Thank you very much for your co-operation

THE FOLLOWING QUESTIONS ASK ABOUT YOUR DEMOGRAPHIC

CHARACTERISTICS

Q1. Age: _ _ _ years old

Q2. Gender:

male

female

Q3. Ethnic origin/race:

African/Black

Indian/Asian

Coloured

other (specify) _ _ _ _ _

White

Q4. Marital status:

never married

widowed

married / domestic partner

separated / divorced

Q5. Highest level of education:

no schooling

some secondary school

tertiary education completed

some primary school

secondary school completed

primary school completed

some tertiary education

Q6. Where do you live most of the year?

your own home / flat

nursing home

home of a friend / family member

Other (specify) _ _ _ _ _

retirement home

Q7. How many people live with you?

I live alone

1 person

2 persons



- 3 persons 4 persons 5 or more persons

Q8. Location of your house:

- urban rural

Q9. Your current employment status:

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

THE FOLLOWING QUESTIONS ASK ABOUT YOUR SPINAL CORD INJURY

Q10. When did you sustain your spinal cord injury?

Q.11 What is the level of your spinal cord injury?



THE FOLLOWING QUESTIONS ASK ABOUT HELP AVAILABLE FOR PEOPLE WITH DISABILITIES

Q12. Do you know of any organisations programmes/centres in your community that help people with disabilities?

- Yes No Not sure
 If Yes specify _ _ _ _ _

Q13. What type of services do they provide? (Tick as many as you want to)

- Counselling Health education HIV/AIDS Programmes
 Recreation and games I don't know

Q14. Do you know of any people with disabilities who have been trained to help other disabled people concerning their health and other problems?

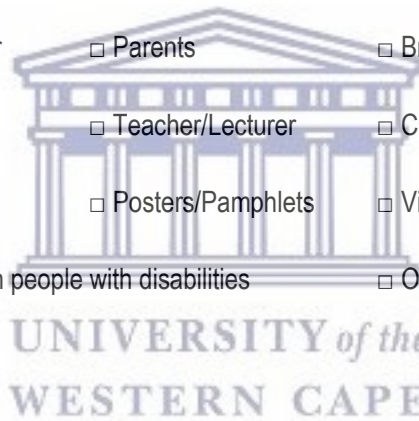
- Yes No Not sure

Q18. Have you ever gone to any of these people (disabled person trained to assist) for help and advice?

- Yes No

Q15. What are your main sources of knowledge/information about HIV/AIDS? (tick as many as you think answers the question)

- Television Radio Friends/Peers
 Partner Health worker Civil Society Organisation
 Peer educator/Counsellor Parents Brothers/sisters
 School Teacher/Lecturer Church/Mosque/Synagogue
 Newspaper/Magazines Posters/Pamphlets Video/DVD
 Organisation working with people with disabilities Other (specify) _____



THE FOLLOWING QUESTIONS ASK ABOUT YOUR GENERAL HEALTH BEHAVIOURS

Q16. Do you currently smoke?

- Yes No

Q17. Do you currently drink alcohol?

- Yes No

Q18. Do you currently use drugs?

- Yes No

THE FOLLOWING QUESTIONS ASK ABOUT SEXUAL BEHAVIOUR

Q19. Have you ever had sexual intercourse?

- Yes No

Q20. How old were you when you had sexual intercourse for the first time?

- I have never had sexual intercourse Age _____

Q21. During your life, how many people have you had sexual intercourse with?

- I have never had sexual intercourse No of people _____

Q22. Do you currently have a partner? (boyfriend/girlfriend/husband or wife)

- Yes No

Q23. Have you had sexual intercourse since your injury?

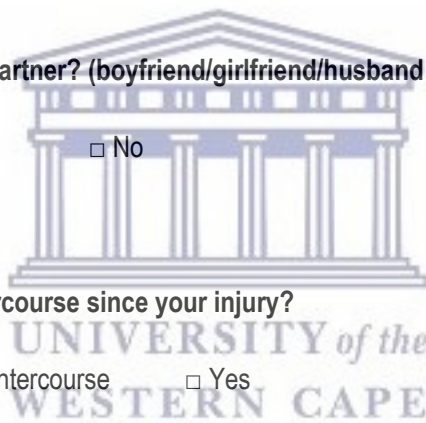
- I have never had sexual intercourse Yes No

Q24. With how many people have you had sexual intercourse since your injury?

- I have never had sexual intercourse No sexual intercourse since my injury
 No of people _____

Q25. The last time you had sexual intercourse, did you or your partner use a condom?

- I have never had sexual intercourse Yes No



Q26. THE FOLLOWING QUESTIONS ASK ABOUT YOUR KNOWLEDGE OF HIV/AIDS

Circle the appropriate response with the following statements as True, False or Don't Know. Do not guess

1. Coughing and sneezing DO NOT spread HIV?	TRUE	FALSE	Don't Know
2. A person can get HIV by sharing a glass of water with some who has HIV?	TRUE	FALSE	Don't Know
3. Pulling out the penis before a man climaxes keeps a woman from getting HIV during sex.	TRUE	FALSE	Don't Know
4. A woman can get HIV if she has anal sex with a man.	TRUE	FALSE	Don't Know
5. Showering or washing one's private parts, after sex keeps a person from getting HIV.	TRUE	FALSE	Don't Know
6. All pregnant women infected with HIV will have babies born with HIV.	TRUE	FALSE	Don't Know
7. People who have been infected with HIV quickly show serious signs of being infected.	TRUE	FALSE	Don't Know
8. There is a vaccine that can stop adults from getting HIV.	TRUE	FALSE	Don't Know
9. People are likely to get HIV by deep kissing, putting their tongue in their partner's mouth, if their partner has HIV.	TRUE	FALSE	Don't Know
10. A woman cannot get HIV if she has sex during her period.	TRUE	FALSE	Don't Know
11. There is a female condom that can help decrease a woman's chance of getting HIV.	TRUE	FALSE	Don't Know
12. A natural skin condom works better against HIV than does latex condom.	TRUE	FALSE	Don't Know
13. A person will not get HIV if she or he is taking antibiotics.	TRUE	FALSE	Don't Know
14. Having sex with more than one partner can increase a person's chance of being infected with HIV.	TRUE	FALSE	Don't Know
15. Taking a test for HIV one week after having Sex will tell a person if she or he has HIV.	TRUE	FALSE	Don't Know
16. A person can get HIV by sitting in a hot tub or a swimming pool with a person who has HIV.	TRUE	FALSE	Don't Know
17. A person can get HIV from oral sex.	TRUE	FALSE	Don't Know
18. Using Vaseline or baby oil with condoms lowers the chance of getting HIV.	TRUE	FALSE	Don't Know


Q27. THE FOLLOWING QUESTIONS ASK ABOUT YOUR KNOWLEDGE OF CONDOMS, YOUR ATTITUDE AND SELF-EFFICACY TO CONDOM USE.

Many people have different opinions about condoms. I want you to tell me if you agree or disagree with the following statements or if you not sure or don't know. **CIRCLE THE APPROPRIATE OPTION**

1. Condoms are ineffective way of preventing HIV and pregnancy.	Agree	Not sure	Don't Know	Disagree
2. A girl can suggest to her boyfriend that he uses a condom.	Agree	Not sure	Don't Know	Disagree
3. If a girl suggested using condoms to her partner, it would seem as if she didn't trust him.	Agree	Not sure	Don't Know	Disagree
4. Condoms reduce sexual pleasure	Agree	Not sure	Don't Know	Disagree
5. If unmarried partners want to have intercourse before marriage, they should use condoms.	Agree	Not sure	Don't Know	Disagree
6. Most of my friends who have sex with someone use condoms regularly.	Agree	Not sure	Don't know	Disagree
7. I think I would succeed in using condoms when having sexual intercourse with my partner.	Agree	Not sure	Don't know	Disagree
8. I would find it difficult to use a condom when having sexual intercourse with my partner.	Agree	Not sure	Don't know	Disagree
9. I would refuse to have sex with someone who is not prepared to use a condom.	Agree	Not sure	Don't know	Disagree

Q28. THE FOLLOWING SECTION ASKS ABOUT YOUR SELF-EFFICACY TO HAVE OR REFUSE SEX

Circle a number from 0 to 5 that is applicable to you, where 0 represent NOT SURE and 5 represent VERY SURE

<p>1. Imagine you and your partner have been having sex without using condoms but now you want to start using one. How sure are you that you could tell your partner to start using condom?</p>	<p>0 1 2 3 4 5</p>						
<p>2. Imagine you that you are having sex with someone you just met. You feel it is important to use condoms. How sure are you that you could tell that person you want to use condoms?</p>	<p>0 1 2 3 4 5</p>						
<p>3. Imagine you and your partner use birth control pills and injection to prevent pregnancy. You want to use condoms to keep from getting HIV. How sure are you that you convince your partner on the need to use condoms?</p>	<p>0 1 2 3 4 5</p>						
<p>4. Imagine going together with your new partner but you have not had sex. He or she wants to have but you don't feel ready. How sure are you that you could wait from having sex until you feel ready?</p>	<p>0 1 2 3 4 5</p>						
<p>5. Do you think you have risk of getting HIV/AIDS?</p>	<table border="1"> <tbody> <tr> <td data-bbox="901 1227 1023 1294">No risk</td> <td data-bbox="1023 1227 1158 1294">small risk</td> <td data-bbox="1158 1227 1410 1294">moderate risk</td> </tr> <tr> <td data-bbox="901 1294 1023 1368">Great risk</td> <td colspan="2" data-bbox="1023 1294 1410 1368">Extreme risk</td> </tr> </tbody> </table>	No risk	small risk	moderate risk	Great risk	Extreme risk	
No risk	small risk	moderate risk					
Great risk	Extreme risk						
<p>6. Why do you think you are at risk? Or why do you think you are not at risk of HIV? Specify</p>							

Q29. THE FOLLOWING SECTION ASKS ABOUT YOUR COMMUNICATION REGARDING SEXUAL MATTERS AND YOUR NEGOTIATION SKILLS WHEN IT COMES TO SEXUAL MATTERS

Think about your partner and answer the following questions with that person in mind .If you do not have a partner, imagine that you have one and answer the following questions with that person in mind. **CIRCLE THE MOST APPROPRIATE NUMBER**

	<i>Strongly Agree</i>	<i>Agree</i>	<i>Neutral</i>	<i>Disagree</i>	<i>Strongly Disagree</i>
1. I would want to know if my partner has ever had an HIV test?					
2. I would ask my partner about his or her past sexual behaviours.	1	2	3	4	5
3. I would want to know if my partner has ever had sexually transmitted infection	1	2	3	4	5
4. I would ask if my partner ever had sex with someone that uses drugs.	1	2	3	4	5
5. My partner always wants to know where I am.	1	2	3	4	5
6. Most of the time, we do what my Partner wants to do.	1	2	3	4	5
7. My partner does what he/she wants even if I object to it.	1	2	3	4	5
8. My partner gets more out of our relationship than I do.	1	2	3	4	5
9. We don't talk about sex, we just do it.	1	2	3	4	5
10. In my opinion, a woman can suggest using condoms just like a man can.	1	2	3	4	5
11. My partner might be having sex with someone else.	1	2	3	4	5

THANK YOU FOR YOUR COOPERATION!