

**SURVIVAL AND SECONDARY MEDICAL CONDITIONS OF  
PERSONS WITH TRAUMATIC SPINAL CORD INJURY  
IN SOUTH AFRICA**

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Master of Science in the Department of Physiotherapy,  
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## ABSTRACT

**Background:** A spinal cord injury (SCI) results in a change, either temporary or permanent, in the cord's normal motor, sensory or autonomic function. In addition, secondary medical complications are common, following an SCI. As such, mortality risk in the spinal cord community remains higher, when compared to the general population. Understanding the complexity of factors related to mortality, remains paramount.

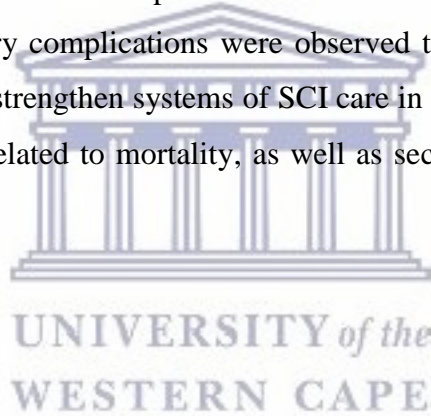
**Aim:** The overarching aim was to assess mortality and secondary medical complications, four years after traumatic spinal cord injury (TSCI) in the City of Cape Town, South Africa. Secondly, factors associated with mortality and the development of secondary medical complications were assessed.

**Methods:** A prospective, population-based design was used. The study population consisted of all respondents with TSCI, who were enrolled in an earlier incidence study that was conducted in 2013/2014. For this follow-up study, an inclusive sampling strategy was used. All eligible respondents (N=145), or a family member of the deceased, were initially telephonically contacted and requested to complete a valid and reliable interview-administered questionnaire, to be completed face-to-face, or telephonically. Of those patients who were deceased, a close family member, or former caretaker was asked to participate in this current study. In order to aid the generalisability of the findings to the immediate source population, every non-responder with information available from baseline data collected in 2013/2014, were accounted for. Descriptive statistics were used to describe the cohort and to present the mortality rate, as well as point-prevalence of secondary medical complications. Inferential statistics, namely, bivariate logistic regression analysis, were used to identify factors associated with mortality and the development of secondary medical complications.

**Results:** The response rate of the initial 145 persons was 60% (N=87). Of the 87 accounted participants, a total number of 55 persons (63%) were alive and completed the full survey on health status and functioning, 21 persons (24%) were deceased by the follow-up date, and 11 people (13%) were classified as alive, but did not complete the survey due to declining participation in the follow up study or did not arrive for their scheduled interview. There were no differences in the key variables, namely, gender, age, as well as level and completeness of injury, found between the responders and non-responders. The mortality rate was 24%, four

years post injury, and the significant factors related to mortality, four years post injury, were that persons with complete spinal cord injury were four times more likely to succumb (complete as reference: OR: 0.2; 95% confidence interval (CI): 0.07-0.58), and those having transport related injuries were at almost nine times less at risk of mortality, in comparison to falls (fall aetiology as reference: OR: 0.11; 95%CI: 0.01-0.76). Concerning medical complications at four years, 69% of the respondents had at least one medical complication, while the most common secondary medical complications, at four years after injury, were pain (44%), muscle spasms (42%), sleeping problems (31%) and autonomic dysreflexia (29%). The factors related to developing a medical complication, four years post injury, were completeness of injury, where those with incomplete injuries had a four-fold likelihood (OR: 0.18; 95%CI:0.05-0.61) of not developing a complication, and having a longer length of acute hospitalisation (OR: 1.04; 95% CI: 1.01-1.07)

**Conclusion:** Almost one quarter of the respondents with TSCI were deceased, four years after injury. Additionally, secondary complications were observed to be highly prevalent at four years after injury. In order to strengthen systems of SCI care in South Africa, particular focus should be placed on factors related to mortality, as well as secondary medical complication development.



## KEYWORDS

Disease-related factors

Health Status

Modifiable risk factors

Mortality

Non-modifiable risk factors

Preventative strategies

Quality of care

Risk indicators

Secondary medical complications

South Africa

Traumatic Spinal Cord Injury

Western Cape



## ABBREVIATIONS

ADL	-	Activities of Daily Living
CBR	-	Community-based rehabilitation
Cis	-	Confidence intervals
ICF	-	International Classification of Functioning, Disability and Health
InSCI	-	The International Spinal Cord Injury community survey
NRP	-	National Rehabilitation Policy
ORs	-	Odds Ratios
RSA	-	Republic of South Africa
SCI	-	Spinal cord injury
SCI-SCS	-	Spinal Cord Injury Secondary Health Conditions Scale
SMR	-	Standardized Mortality Ratio
TSCI	-	Traumatic spinal cord injury
UNCRPD	-	The United Nations Convention on the Rights of Persons with Disabilities
UTI	-	Urinary tract infections
WCRC	-	Western Cape Rehabilitation Centre
WHO	-	World Health Organisation



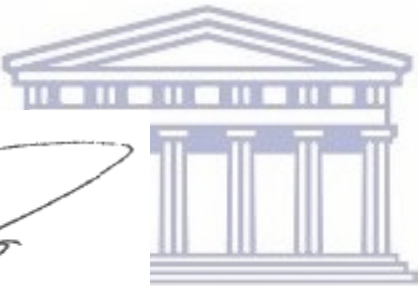
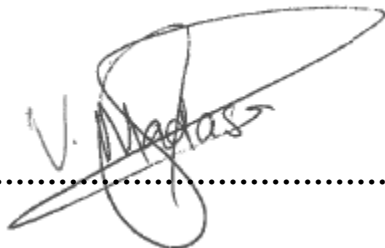
## DECLARATION

I declare that *Survival and secondary medical conditions of persons with traumatic spinal cord injury in South Africa*, is my own work, has not been submitted for any degree, or examination, at any other university, and all the resources I have used, or quoted, have been indicated, and acknowledged by complete references.

**Name:** Vuyolwethu Madasa

**Date:** November 2018

**Signed:** .....



UNIVERSITY of the  
WESTERN CAPE

## DEDICATION

This thesis is dedicated to my mother, Nosisi Emma-Rose Madasa, and my grandmother, Nontuthuzelo Florence Madasa, whose unconditional love, support and prayers have carried me, and made this possible. Mom, at the age of 51, you got your first diploma, after putting everyone else through school and varsity, and for that, I will always be eternally be grateful. Thank you for constantly cheering me on and supporting my dreams.



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First and foremost, I would like to thank my heavenly Father, for without Him, none of this would have been possible. Thank you for opening doors that I never even thought a woman, like me, would be able to walk through.

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Without the love and support of my family and friends, the midnight phone calls, prayer sessions and words of encouragement, I would not have gotten this far. I am really blessed and grateful, may the good Lord richly bless each and every one of you, thank you.

To my colleagues and friends that have now turned into my UWC family, for lack of a better word to express my sincere thanks and heartfelt gratitude, *thank you* all so much. The words of encouragement and the emotional support was much appreciated. Thank you for making my transition from clinical to academia a smooth one.

Lastly, I would also like express my sincere gratitude and thanks to The South African Medical Research Council (Research Capacity Development Initiative) for the full financial support for the duration of my studies. Without their funding, this journey would not have been possible.

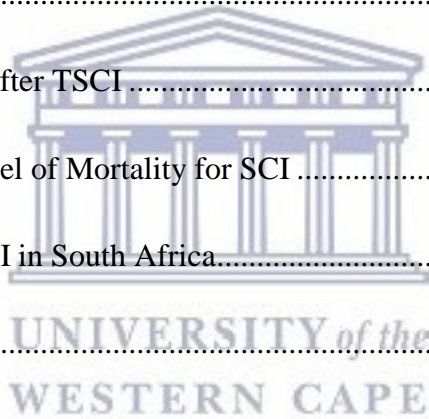


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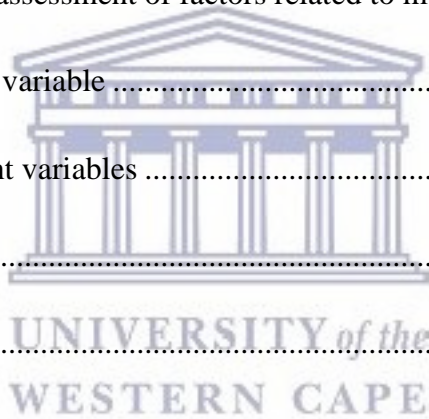
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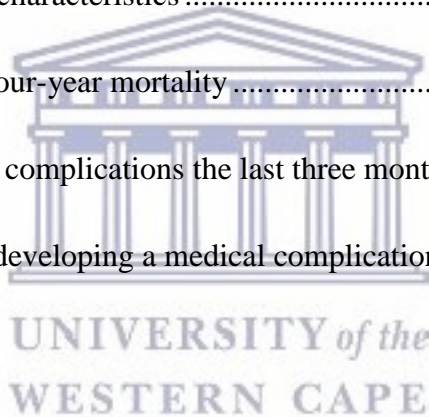


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# CHAPTER ONE

## INTRODUCTION

### 1.1. Background

In 2012, the World Health Organization (WHO) estimated that, every year, among adults around the world, between 250 000 and 500 000 people suffer a spinal cord injury, with a male-to-female ratio of at least 2:1 (World Health Organization [WHO], 2012). A spinal cord injury (SCI) is defined as an insult to the spinal cord, resulting in a change to the normal motor, sensory, or autonomic function of the cord, either temporarily or permanently (Nas, Yazmalar, Şah, Aydın & Öneş, 2015). Patients with SCIs usually have permanent and often devastating neurologic deficits and disability, predisposing them to early deaths permanently (Nas, Yazmalar, Şah, Aydın & Öneş, 2015).

A spinal cord injury can be non-traumatic, [for example, infectious and autoimmune causes, such as loss of blood supply, compression by a cancer, or slow degeneration of the spinal bones], or traumatic [for example, a traumatic impact, such as a car accident, fall, or violent act] (Wang, Singh & Fehlings, 2017). For the purpose of this research, the researcher only focuses on traumatic spinal cord injury (TSCI), due to the slightly more homogenous nature of injury onset, in comparison to non-traumatic spinal cord injury (Olckers, 2017). The management of this health condition depends on the implementation of timeous life-saving interventions, such as providing appropriate pre-hospital, emergency care, surgical decompression/stabilisation of the spinal cord, and multi-disciplinary care (Ahidjo, Olayinka, Ayokunle, Mustapha, Sulaiman & Gbolahan, 2011). Due to the complexity of problems in the wake of a SCI, a specialized approach to managing the injury is advocated, which has been adopted in many countries (Joseph, Scriba, Wilson, Mothabeng & Theron, 2017).

In developed countries, specialized systems have been implemented, resulting in increased survival rates, lower first year mortality rates, and better neurological recovery (WHO, 2012; Furlan, Noonan, Cadotte & Fehlings, 2011). Mortality risk is highest in the first year after injury, and remains high. Compared to the general (healthy) population, people with SCIs are 2 to 5 times more likely to die prematurely (WHO, 2012). Acute mortality has nearly decreased to zero in parts of the industrialized world, where a high quality of specialized care and acute

transportation are available, providing direct evidence that systematic approaches are superior in SCI management (Divanoglou, Seiger & Levi, 2010; Divanoglou, Westgren, Seiger, Hulting & Levi, R, 2010; Parent, Barchi, Lebreton, Casha & Fehlings, 2011).

In developing countries, an increase in the mortality of patients with SCIs has been documented, due to the lack of specialized and coordinated systems for persons with SCIs (Löfvenmark, Norrbrink, Nilsson-Wikmar, Hultling, Chakandinakira & Hasselberg, 2015). A two-year follow-up study, conducted in Botswana, observed a mortality rate of 20% for persons with TSCIs, as well as causes of death related to preventable secondary medical complications (Löfvenmark *et al.*, 2015). In addition, the causes of death referred to, following the acute phase, were due to preventable secondary complications, namely, infections from untreated pressure ulcers, respiratory complications, and urinary tract infections (Löfvenmark *et al.*, 2015). Therefore, the researcher is of the opinion that the introduction of specialized care in developing countries, could contribute to better hospital efficiency and patient-centred outcomes. In addition, the researcher observed that there is scant information and data on mortality, its causes, as well as the functioning of persons with SCI in South Africa (Joseph *et al.*, 2017).

South Africa has a high incidence of TSCI, when compared to previously estimated figures for the country (Joseph & Nilsson-Wikmar, 2016); however, no reliable sources existed until recently. According to the literature, the incidences and causes of SCI have already been established in the Cape Metropolitan area, where the annual incidence rate of SCI was 75.6 per million persons, with the majority population group affected being males, aged 18 to 30 (Joseph, Delcarne, Vlok, Wahman, Phillips & Nilsson-Wikmar, 2015). The main cause of injury was determined to be assault (59.3%), followed by transport causes and falls (Joseph *et al.*, 2015). With reference to the ‘assault’ category, 52% of injuries were caused by gunshots, 33% were due to stab wounds, and 15%, as a result of interpersonal violence, involving blunt force trauma. There is a need for more holistic research on TSCI epidemiology in South Africa, as the available research is only confined to one province, and may not necessarily represent the whole country (Joseph *et al.*, 2015; Joseph *et al.*, 2017).

Due to the unique etiologic profile of injuries in South Africa, more information on survival, causes of death, and functioning is required, in order to assess whether current management plans continue to apply (Joseph *et al.*, 2015). The researcher is of the opinion that there is a



great need to study mortality, as none of the studies reporting on mortality had a similar patient group, with similar characteristics. The South African etiologic profile is different to that of the international studies, tabulated and referred to. Therefore, studying mortality is important, to inform public health care services of South Africa, and thereby improve medical care of persons living with TSCI.

The South African TSCI population appears to be unique, in more ways than one, for example, the cause of injury is associated with violent activities, the majority of which are gunshot injuries (Joseph *et al.*, 2015; Joseph *et al.*, 2017). The cost associated with such injuries, from site of injury, trauma unit, theatre, intensive care unit, longer hospital stay and prolonged rehabilitation time, needs to be evaluated, since these individuals often present with co-acute health conditions (Furlan *et al.*, 2011). The researcher is of the opinion that there is a great need for primary prevention strategies, to target younger men exposed to violent activities; however, since these injuries are still occurring, the need exists to augment services that target survival, and enhance functioning.

Internationally, most post-SCI deaths appear to be due to the development of secondary medical complications, of which the most common ones are respiratory diseases, pain, spasticity, urinary tract infections, pressure ulcers and autonomic dysreflexia (Kalpakjian, Scelza, Forchheimer & Toussaint, 2007). In South Africa, pressure ulcers, atelectasis, pneumonia and urinary tract infections are the most common secondary medical complications, following acute TSCI (Joseph & Nilsson Wikmar, 2016). With this identification of risk factors it is important to prioritise and implement preventive strategies. Another study on the same cohort as the previous study revealed that secondary medical complications were prevalent *during* the acute phase (Joseph & Nilsson Wikmar, 2016). Therefore, the researcher maintains that it is important to identify the prevalence of secondary medical complications, in the long term, as well as assess its association with mortality status.

There are both modifiable and non-modifiable risks indicators that could cause loss of life. However, according to IPSCI Report (WHO, 2012), most persons with TSCI succumb to causes that could have been prevented. In South Africa, therefore, the researcher asserts that the need exists to determine the prevalence of the most common secondary medical complications, as well as their effect on functioning, which is information required to strengthen systems of care for persons with TSCI.

A model has been developed to understand factors related to mortality/secondary risk indicators. Four levels have been identified, namely: demographic and injury characteristics, psychological and environmental factors, health behaviours, and health status (Krause, Saunders, DiPiro & Reed, 2013). These factors should be understood in terms of their propensity to be altered. An example of a modifiable environmental factor could be early surgery. An early surgical operation, defined by a cut-off of 72 hours, is associated with shorter length of stay in hospital, shorter length of stay in the intensive care unit, lower mortality rate, lower frequency of secondary complications after SCI, better neurological recovery, and less costly care (Furlan *et al.*, 2011). Applying the risk model of Krause *et al.* (2013) for mortality and secondary medical conditions, could assist with the development of a healthcare decision-making model in the future.

## **1.2. Problem statement**

The survival status of persons with devastating injuries, or diseases, is a hallmark feature of specialised and comprehensive health systems. Survival of persons with SCI/TSCI in developed contexts is approaching that of the general population for certain sub-groups. Very little is known about survival status, or its inverse-mortality rate in South Africa. This information is required to strengthen systems of care, with the aim of re-integrating persons with TSCI, back into society, enabling them to become part of the economic workforce. In addition, very few centres provide specialized care, which is the gateway to optimal survival and patient-centred outcomes. Consequently, there is scant information on the health status and functioning of long-term survivors of SCI in South Africa, information that is essential to build efficient systems of care (Joseph & Nilsson Wikmar, 2016; Joseph *et al.*, 2017).

This study, therefore, aims to address the lack of knowledge, regarding modifiable and non-modifiable risk indicators for loss of life, at least four years after injury, as well as determine the health status (secondary medical complications) of patients, who had been integrated back into society.

## **1.3. Aim**

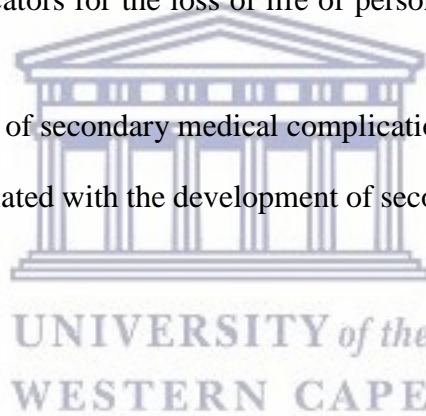
To determine the mortality and secondary medical complications (health status) after TSCI in the City of Cape Town, South Africa.

#### 1.4. Objectives

- To determine the mortality rate, four years after a TSCI;
- To determine risk indicators for the loss of life of persons with TSCI, four years after injury;
- To determine the prevalence of secondary medical complications, four years after TSCI, using a three-month window period; and
- To determine the association between disease-related factors and the development of secondary medical complications, at four year follow up.

#### 1.5. Research questions

- What is the mortality rate, four years after a TSCI?
- What are the risk indicators for the loss of life of persons with TSCI, four years after injury?
- What is the prevalence of secondary medical complications, four years after TSCI?
- What factors are associated with the development of secondary medical complications, at four year follow up?



#### 1.6. Significance of the study

Exploring mortality and secondary medical complications (health status) after TSCI of persons living in the City of Cape Town, South Africa, could be used to influence the improvement in healthcare services throughout the chain-of-care. In turn, this could reduce the high cost of managing patients with TSCI, and result in improved patient outcomes, such as being part of society again, and contributing through their return-to-work. Results from this study can be used to develop protocols and facilitate the implementation of it to prevent secondary medical complications. In addition, this study could provide policy makers and health care administrators in South Africa with evidence-based information on the prevalence of secondary medical complications, post-TSCI, risk indicators for the loss of life of persons with TSCI, as well as the association between disease-related factors and the development of secondary medical complications. Ultimately, the findings of this study could be used to design feasible interventions for the prevention modifiable secondary medical complications in TSCI, as well as the cost effective management of patients with TSCI.

## 1.7. Research methodology

A quantitative research methodology was employed to answer the relevant research questions and achieve the study aim and objectives. More specifically a cross sectional design, founded on a previous population-based design was selected, above other designs, such as a retrospective design, as the results deriving from this current study could aid generalizability of the findings to the immediate catchment area, and could further assist in establishing the causality of outcomes, such as mortality and secondary complication development. The study population and sampling techniques applied are discussed, in detail, in Chapter 3. The data collection procedure and instrumentation used in this current study are reviewed from a psychometric standpoint, and the data analysis procedure is also discussed in detail. Lastly, the relevant ethical considerations, ethical principles, regarding research conducted on humans, as per the Helsinki Declaration, are discussed.

## 1.8. Ethical considerations

Ethical clearance to conduct this current study was obtained from the University of the Western Cape (Ethics reference number BM17/6/11 – Appendix 1). The participants were issued with an information sheet (Appendices 2-7) and a consent form (Appendices 11-13), available in English, Africans and IsiXhosa. Subsequently, the individual-level data, collected from the participants, were captured and stored on a password-protected computer. If any harm was caused, or the participants experienced any problems that the researcher was unable to resolve, an appropriate referral was made. Finally, participants had the right to withdraw at any time, during the research process, without facing any negative consequences.

## 1.9. Definitions of terms

- **TSCI** – is a traumatic spinal cord injury, caused by a traumatic event/incident, such as a car accident, fall or violent act. It typically results in temporary, or permanent deficits, in sensory, motor, and autonomic functions, below the level of the lesion (Olckers, 2017).
- **Epidemiology** – is the study of the distribution and determinants of health-related states, or events (including disease), as well as its application to the control of diseases

and other health problems. Epidemiology includes the study of incidence, prevalence, aetiology, mortality and morbidity (Waring *et al.*, 2010).

- **Mortality** – is the number of deaths within a particular period of time [person-time] (Rothman, 2012).
- **Chronic phase** – is the long term phase post-injury, 6 months and more (McDonald & Sadowsky, 2002).
- **Functioning** – is an umbrella term encompassing all body functions, activities and participation (World Health Organization [WHO], 2013).
- **Participation** – is the involvement in a life situation, according to the ICF (WHO, 2013).
- **Impairment** – is a problem in body function, or structure, such as a significant deviation or loss, according to the ICF (WHO, 2013).
- **Activity** – is the execution of a task, or action by an individual (WHO, 2013).
- **Activity Limitations** – are difficulties an individual may have in executing activities (WHO, 2013).
- **Participation Restrictions** – are problems an individual may experience with involvement in life situations (WHO, 2013).
- **Environmental Factors** – make up the physical, social and attitudinal environment, in which people live and conduct their lives (Guilcher, Craven, Lemieux-Charles, Casciaro, McColl & Jaglal, 2013).
- **Secondary medical complications** – is a secondary disease, or condition that develops in the course of a primary disease, or condition, and arises, either as a result of it, or from independent causes. It can either be modifiable or non-modifiable within the context of a spinal cord injury (Guilcher *et al.*, 2013).

## 1.10. Structure of the thesis

### Chapter 1 – Introduction

In this chapter, the researcher introduces the main concepts related to the field of spinal cord injury epidemiology. In addition, a description of health care systems is provided, as a basis for addressing complications and functioning problems with SCIs. The conceptual model,

which frames the study findings, is introduced. The researcher identifies of the lack of knowledge (problem statement), as well as setting the aim, objectives, and research questions. The chapter is concluded with a synopsis of the significance, methodology, ethical considerations, definitions of terms, as well as structure of the thesis.

## **Chapter 2 – Literature Review**

In this chapter, the researcher reviews the relevant literature, in terms of mortality, risk indicators for loss of life of persons with spinal cord injury, the prevalence of secondary medical complications, and the association between disease-related factors and the development of secondary medical complications. In addition, the study's main conceptual model will be unpacked, as well as the South African healthcare system for spinal cord injuries, from prehospital/acute care to rehabilitation. The researcher concludes the chapter with highlights of the disparity in literature.

## **Chapter 3 – Methodology**

In this chapter, the researcher considers the methodological issues relevant to the study. The research setting, in which the study was based, as well as the study design used, are presented. Subsequently, the study population and sampling methods used are discussed. A description of the data collection methods is submitted, including the instrument used in data collection, data collection procedures and issues of reliability and validity. The chapter concludes with an account of the method of data analysis, as well as explanation of how ethical issues were addressed.

## **Chapter 4 – Findings**

The researcher discusses the quantitative data analysis in this chapter, with the findings summarised and presented in tables.

## **Chapter 5 – Overview and Discussion**

In this chapter, the study's main findings are presented, with the relative literature discussed and linked, or the differences highlighted. The findings of the study is linked to the main theoretical framework of the study, Krause's Theoretical Risk and Prevention Model.

## **Chapter 6 – Conclusion, Recommendations and Limitations**

The conclusions are presented, based on the findings and literature for each objective. In addition, recommendations are made on improving systems of SCI care in South Africa, with

particular focus on factors related to mortality and secondary medical complication development.

## CHAPTER TWO

### LITERATURE REVIEW

#### 2.1. Introduction

In this chapter, the researcher reviews the relevant literature relating to mortality, risk indicators for the loss of life of persons with spinal cord injury, the prevalence of secondary medical complications, as well as the associations between disease-related factors and the development of secondary medical complications. The definition of spinal cord injury is explained in detail, including syndromes that can result from spinal cord injuries. The incidence, prevalence and aetiology of traumatic spinal cord injuries are discussed and tabulated. *Incidence* conveys information about the risk of contracting the disease, *prevalence* indicates how widespread the disease is, and *aetiology* refers to the cause of the disease. The literature on the mortality of spinal cord injury is discussed and tabulated, along with the leading causes of the loss of life, per region. The researcher explores violence in South Africa and the risk of mortality, after traumatic spinal cord injury. The study's main conceptual model, Krause's theoretical risk model of mortality for spinal cord injury, is unpacked. Finally, South Africa's healthcare system for spinal cord injuries, including prehospital/acute care, rehabilitation, as well as the disparities in literature, are highlighted.

#### 2.2. Definition of a Spinal cord injury (SCI)

A spinal cord injury (SCI) is an insult to the spinal cord, resulting in a change, either temporary or permanent, in the cord's normal motor, sensory or autonomic function (Mbori, Chuan, Feng, Alizada & Zhan, 2016). A spinal cord injury is a traumatic event that affects a patient's physical, psychological, and social well-being, and places substantial financial burden on health care systems. Syndromes of spinal cord injury could occur immediately, following trauma due to TSCI, for example, central cord syndrome, anterior cord syndrome, conus medullaris and cauda equina. Central cord syndrome usually presents after a hyperextension injury of the cervical spine, leading to the impingement of the spinal cord, affecting mostly

males, with a prevalence of 15%-25% in the United States of America (Stobart Gallagher & Gillis, 2018). An anterior cord syndrome is characterized by immediate complete paralysis, with hypaesthesia and hyperalgesia. This syndrome may be the result of acute anterior spinal cord compression by a dislocated bone fragment, herniated disc, or actual destruction of the anterior portion of the cord (Molliqaj, Payer, Schaller & Tessitore, 2014). Conus medullaris syndrome and cauda equina syndrome are complex neurological disorders that can be manifested through a variety of symptoms, namely, patients may present with back pain, unilateral or bilateral leg pain, paraesthesia and weakness, perineum or saddle anaesthesia, and rectal and/or urinary incontinence, or dysfunction (Harrop, Hunt & Vaccaro, 2004).

### **2.3. Prevalence of Traumatic spinal cord injury (TSCI)**

Every year, thousands of people sustain TSCIs. The prevalence and causation of SCIs differ in developing and developed countries, suggesting that the management and preventative strategies need to be tailored to regional trends (WHO, 2012). According to the World Health Organization, the number of persons suffering from SCIs (prevalence) around the world is estimated between 250 000 and 500 000, with the majority caused by preventable factors, such as road traffic accidents, falls or violence. No reliable record of global prevalence exists, but the estimated annual global incidence is 40 to 80 cases per million population (WHO, 2013). Up to 90% of these cases are due to traumatic causes; however, the proportion of non-traumatic spinal cord injury appears to be escalating (WHO, 2013). The prevalence of SCIs in developing countries is estimated at 25.5/million/year (95% CI: 21.7-29.4/million/year) (Rahimi-Movaghar *et al.*, 2013). In South Africa, the incidence rate of TSCI was estimated to be 75.6 per million persons, which is among the highest in the world (Joseph *et al.*; 2015).

There is a significant number of studies that have attempted to quantify worldwide prevalence of SCIs; however, several issues have prevented an accurate estimate, as, currently, no standardized method of assessment exists, across regions (Sundstrøm, Asbjørnsen, Habiba, Sunde & Wester, 2014). Instead, the estimates for some countries have been generalised from numbers obtained in either urban or rural areas, and therefore may not be entirely representative of the SCI population (Farry & Baxter, 2010). A large proportion of global prevalence data emanate from developed nations, such as Spain and the United States of America, with limited information from developing continents, namely, Africa, South America, and Asia (WHO, 2012). In addition, given that there is such a high mortality rate at the scene of the accident, as



well as during patient retrieval and transport, many studies have underestimated figures (Singh, Tetreault, Kalsi-Ryan, Nouri & Fehlings, 2014).

A limited review of regional papers, reporting on the incidence and prevalence of TSCIs, is presented in the following Table 2.1.

**Table 2.1: The review of regional papers reporting on TSCI incidence and prevalence**

Author(s)	Study Type	Title	Country	Year	Incidence	Prevalence
Ning, G-z., Yu, T-q., Feng, S-q., Zhou, X-h., Ban, D-x., Liu, Y. & Jiao, X-x.	A retrospective epidemiological study	Epidemiology of traumatic spinal cord injury in Tianjin, China	China	2011	23.7 per million	
Furlan, J.C., Sakakibara, B.M., Miller, W.C. & Krassioukov, A.V.	Literature Review	Global Incidence and Prevalence of Traumatic Spinal Cord Injury	Global	2013	8.0 to 246.0 cases per million inhabitants per year	236.0 to 1,298.0 per million inhabitants
Pickett, G.E., Campos-Benitez, M., Keller, J.L. & Duggal, N.	Retrospective review	Epidemiology of Traumatic Spinal Cord Injury in Canada	Canada	2006	42.4 per million for adults aged 15–64 years 51.4 per million for those 65 years and older.	
Lee, B.B., Cripps, R.A., Fitzharris, M. & Wing, P.C.	Literature review	The global map for traumatic spinal cord injury epidemiology: update 2011, global incidence rate	Global	2014	Incident rate is estimated at 23 TSCI cases per million	The prevalence is between 236 to 4187 per million
Jazayeri, S., Beygi, S., Shokraneh, F., Hagen, E. & Rahimi-Movaghar, V.	Systematic review	Incidence of traumatic spinal cord injury worldwide: a systematic review	Global	2015	Incidence of TSCI ranges from 3.6 to 195.4 patients per million	
Löfvenmark, I., Norrbrink, C., Nilsson-Wikmar, L., Hultling, C., Chakandinakira, S. & Hasselberg, M.	Descriptive study with a cross-sectional design.	Traumatic spinal cord injury in Botswana: characteristics, aetiology and mortality	Botswana	2015	Annual incidence was 13 per million population	
Joseph, C., Delcarne, A., Vlok, I., Wahman, K., Phillips, J. & Nilsson Wikmar, L.	A prospective, population-based study	Incidence and aetiology of traumatic spinal cord injury in Cape Town, South Africa: a prospective,	South Africa	2015	The crude incidence rate was 75.6 per million	

		population-based study				
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#### 2.4. Aetiology of SCIs

Currently, the most common causes of spinal cord injuries, internationally, are preventable causes, such as road traffic crashes, falls or violence (WHO, 2012). However, South Africa has a different aetiology to that of the world, as violent acts, such as gunshot and stab wounds, are the leading causes of TSCIs (Joseph & Nilsson Wikmar, 2016). The incidences with gunshot injuries involve significantly more complications than the other group, and the hospital stay is significantly longer (Joseph, 2017), which inflicts a financial strain on the healthcare system, and imposes physical, emotional and psychological effects on the patient.

The incidence, prevalence, and causation of SCI differ in developing and developed countries, and suggest that the management and preventative strategies need to be tailored to regional trends (Singh *et al.*, 2014). Car accidents are the leading cause of injury in developed countries, whereas falls are the leading cause in developing countries (Chiu, Lin, Lam, Chu, Chiang & Tsai, 2010). However, historically, road traffic crashes (RTC) have been the leading cause of TSCIs, globally, and in some high-income countries, fall injuries have increased with the ageing of the population, and currently, constitute the primary cause of TSCIs (Löfvenmark *et al.*, 2015; Chiu, Lin, Lam, Chu, Chiang & Tsai, 2010). According to the researcher, the incidence and aetiology require a different preventative approach, and suggest a collaboration between the Health Department, Education Department, Justice Department, as well as Social Development.

#### 2.5. Mortality

Acute mortality has decreased to almost zero in parts of the industrialized world, with the increased availability and quality of specialized care and acute transportation (Divanoglou, Seiger & Levi, 2010). Mortality rates vary according to countries, with certain first world countries recording a 50-year follow-up period, in which 80% of patients survived, at least 10 years, post injury; however, these high rates of survival occur in contexts where specialised systems exist (Furlan *et al.*, 2011).

In South Africa, there is a need to establish the mortality rate, given the unique patient profile, as well as the lack of equitable, accessible specialised TSCI services, and the available literature, either is outdated, or not relevant to the country. South Africa is a developing country in Africa, faced with a high unemployment rate and increasing crime, which has resulted in violence and violence-related injuries becoming the second leading cause for loss of life, as well as lost disability-adjusted life years, in the country (Seedat, Van Niekerk, Jewkes, Suffla & Ratele, 2009). Mortality and longevity studies of spinal cord injuries (SCI) are crucial, to inform healthcare systems and policies (Chamberlain, Meier, Mader, Von Groote & Brinkhof, 2015). The mortality from spinal cord injuries, and related causes of death, are illustrated in Table 2.2 below.

**Table 2.2: The mortality in spinal cord injuries and related leading causes of death**

Article	Year	Author(s)	Study type	Country	Mortality rate	Leading cause of death
Mortality following spinal cord injury	1998	Yeo, J.D., Walsh, J., Rutkowski, S., Soden, R., Craven, M. & Middleton, J.	Cohort	Australia	SMR* 2.4	Injury type: Level of lesion and severity of injury
Recent trends in mortality and causes of death among persons with spinal cord injury	1999	De Vivo, M.J., Stuart Krause, J. & Lammertse, D.P.	Cohort	USA	Mortality rates increased by 33% 1993-1998	Respiratory disease
A prospective assessment of mortality in chronic spinal cord injury	2005	Garshick, E., Kelley, A., Cohen, S.A., Garrison, A., Tun, C.G., Gagnon, D. & Brown, R.	Prospective mortality study	Boston-USA	SMR 1.47	Diseases of the circulatory system and respiratory system
Long-term survival in spinal cord injury: a fifty year investigation	1998	Frankel, H.L., Coll, J.R., Charlifue, S.W., Whiteneck, G.G., Gardner, B.P., Jamous, M.A., Krishnan, K.R., Nuseibeh, I., Savic, G. & Sett, P.	Population-based	Great Britain-UK	SMR Age: (0-30) 1.99 (31-45) 4.58 (46-60) 1.39 (61+) 1.37	Respiratory diseases
Mortality after spinal cord injury in Norway	2007	Lidal, I.B., Snekkevik, H., Aamodt, G., Hjeltnes, N., Stanghelle, J.K. & Biering-Sørensen, F.	A cross-sectional study	Norway	SMR was 1.8 for men and 4.9 for women	Pneumonia/ influenza
Late Mortality During the First Year After Acute Traumatic Spinal Cord Injury: A Prospective, Population-Based Study	2010	Divanoglou, A., Westgren, N., Seiger, A., Hulting, C. & Levi, R.	Prospective, Population-Based Study	Sweden	Mortality rate after acute TSCI : 20% in Thessaloniki & 0% in Stockholm	Higher age and presence of comorbid spinal disorders
Traumatic spinal cord injury in Botswana: characteristics, aetiology and mortality	2015	Löfvenmark, I., Norrbrink, C., Nilsson-Wikmar, L., Hulting, C., Chakandinakira, S. & Hasselberg, M.	Descriptive study with a cross-sectional design	Botswana	Mortality Rate: 20%	Tetraplegia
Survival and cause of death after traumatic spinal cord injury	1997	Hartkopp, A., Brønnum-Hansen, H., Seidenschnur, A. M., & Biering-Sørensen, F.	Retrospective study	Denmark	SMR 2.15	Septicaemia, pneumonia

A long-term epidemiological survey from Denmark						
Mortality and causes of death after traumatic spinal cord injury in Estonia	2013	Sabre, L., Rekan, T., Asser, T. & Kõrv, J.	Retrospective population-based study	Estonia	SMR-2.81	Cardiovascular disease, pneumonia, genitourinary tract infection and infections related to pressure ulcers, and suicide

\*SMR-Standard Mortality Ratio

## 2.6. Violence

*Violence and non-intentional injuries are the second leading cause of loss of life and disability in South Africa.* The social dynamics that support violence are, widespread poverty, unemployment, and income inequality; patriarchal notions of masculinity that promote toughness, risk-taking, and defence of honour; exposure to abuse in childhood and weak parenting; access to firearms; widespread alcohol misuse; and weaknesses in the mechanisms of law enforcement (Seedat *et al.*, 2009). An estimated 3.5 million people seek health care for non-fatal injuries each year, of which half are caused by violence (Seedat *et al.*, 2009).

In South Africa, violence/assault has been identified as the leading cause of TSCI (59.3%), followed by transportation (26.3%) and falls (11.7%) (Joseph *et al.*, 2015). South Africa has an unprecedented burden of morbidity and mortality, arising from violence and injury, with an overall injury loss of life rate of 157.8 per 100 000 population, nearly twice the global average (Seedat *et al.*, 2009). In South Africa, the post-apartheid era, constitutional racial segregation and exploitation has submitted to a non-racial democracy; however, the political conflict may have subsided, but high levels of interpersonal violence remain, incited by rapid urbanization, and on-going socio-economic disparities (Norman, Matzopoulos, Groenewald & Bradshaw, 2007).

## 2.7. Risk factors of mortality after TSCI

As mentioned previously, mortality and longevity studies are crucial to inform healthcare systems and policies, and among those studies that investigated mortality trends, are high resourced countries, with extended periods of follow-up (Chamberlain *et al.*, 2015). Individuals with spinal cord injuries, are two to five times more likely to die prematurely, than people without spinal cord injuries, with the worse survival rates in low- and middle-income countries (WHO, 2012). Mortality in TSCIs is often due to unmodifiable (severity of injury, age at onset,

and co-morbidity) and modifiable factors (secondary complications and early surgery and treatment).

As age increases, the risk of mortality increases by 6%, and the overall life expectancy among the SCI population is reduced (Chamberlain *et al.*, 2015). In Nigeria, a study was conducted to investigate short term (within six months post-injury) causes of mortality after TSCIs. The findings of that study revealed that the most common complications and causes of mortality following SCI, were pressure ulcers and respiratory failure, while some of the risk factors associated with mortality were age, GCS<9, cervical spinal injury, and complete neurologic injury (Kawu *et al.*, 2011).

In South Africa, a study identified pressure ulcers and pulmonary complications as the most common secondary medical complications, following acute TSCIs (Joseph & Nilsson Wikmar, 2016). Ultimately, it would appear that a high incidence of secondary complications exist in South Africa, which are markers that may implicate a higher mortality rate; however, these assertions need to be confirmed.

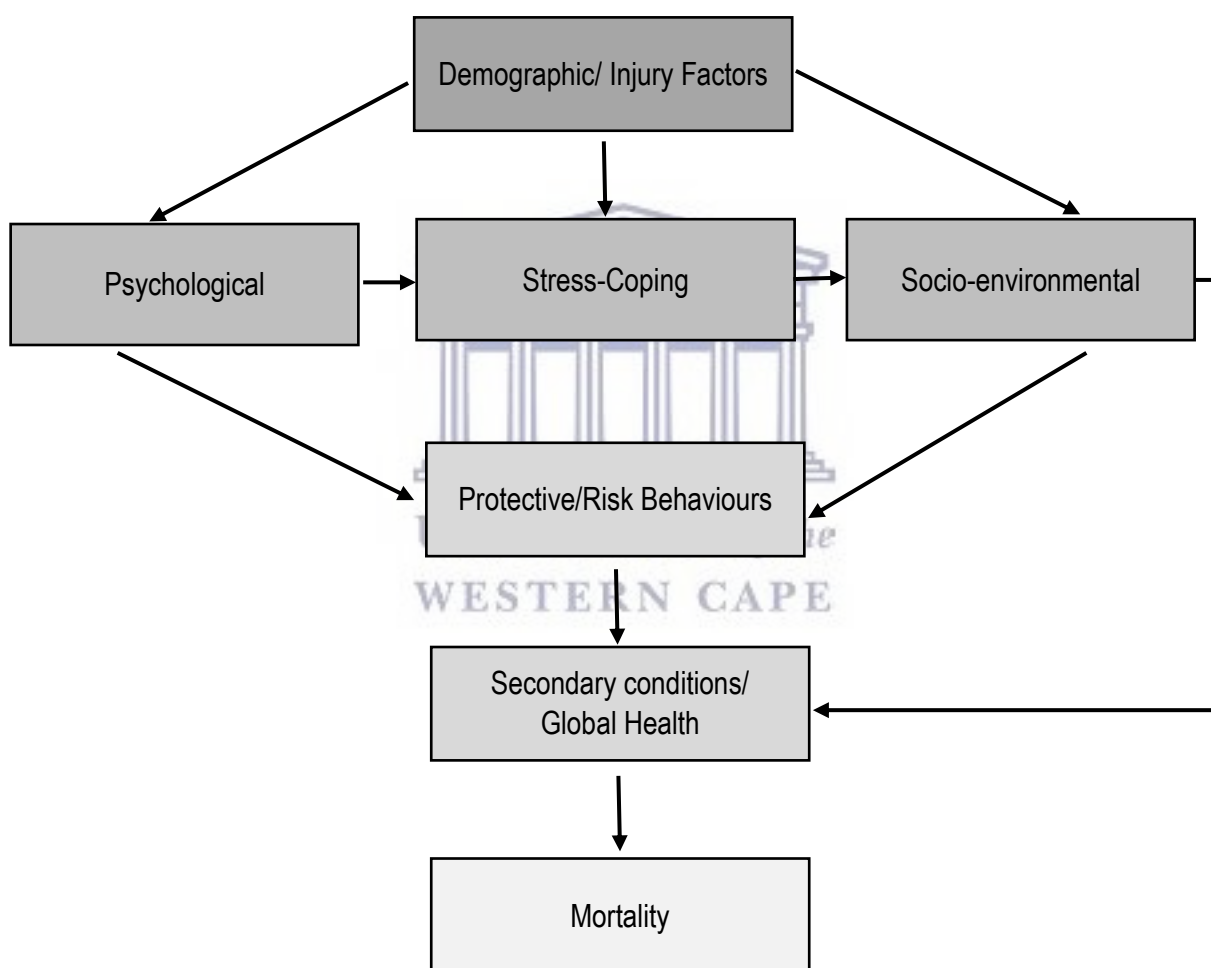
## **2.8. Krause's Theoretical Model of Mortality for SCI**

Spinal cord injury is associated with a lifelong risk of secondary health conditions and mortality; therefore, to prevent mortality and secondary conditions, successfully, as well as promote longevity, the risk factors causing their occurrence must be understood, and strategies developed to address these risk factors (Krause *et al.*, 2013). "Secondary health conditions are defined as physical or psychosocial health conditions, for which the development, or cause, is directly influenced by the presence of a disability, or impairment" (Jensen *et al.*, 2012: p. 374).

Conceptual models are used to assist in the development of prevention strategies, by helping to identify the nature of the secondary health conditions, and guiding research and clinical practice (Krause *et al.*, 2013). In 1996, a Theoretical Risk and Prevention Model (TRPM) was developed as a means of classifying risk and protective factors for mortality and secondary health conditions, as well as identifying points of intervention (Krause *et al.*, 2013). This model categorised factors that predict mortality and secondary health conditions into 4 groups

(according to the type, and proximity to mortality), namely, demographic and injury characteristics, psychological and environmental factors, health behaviours, and health status.

In 2011, the model was modified and the predictive factors are now grouped into demographic and disability factors, psychological and socio-environmental factors, an additional path from socio-environmental factors to health outcomes, and a direct path from behaviours to mortality, to account for mortality related to intentional injuries and homicide (Krause & Saunders, 2012). In this current study, a particular focus is placed on demographic/injury factors and secondary conditions.



**Figure 2.1: Krause's theoretical risk model**

## **2.9. Health care system for SCI in South Africa**

The SCI care in the South African healthcare context is under development, and, to date, a specialised acute SCI unit has been established in the Western Cape; however, only a few of the 9 provinces in South Africa have the organizational capacity and resources to provide a more comprehensive package of care for survivors of SCI (Joseph, 2017). Such services are available and accessible, though limited, to those in urban areas, but not those in rural areas.

In Cape Town, the only government-funded rehabilitation centre manages 420 people with spinal cord injuries, annually. Admission is based on the patients' location. At times, the patients are first admitted at a hospital closest to them, to be stabilized, and subsequently, referred to the tertiary hospital in the Western Cape with a Spinal Cord Injury unit, subject to the availability of beds. After being discharged from hospital, the patients are referred to the one government-funded rehabilitation centre; however, not everyone is accommodated, as the centre has its own admissions criteria, as well as a limited number of beds. Therefore, those in larger and more established/developed urban areas, have access to healthcare and spinal cord rehabilitation. However, transport is a problem, as either the patients cannot afford the cost of transport to attend rehabilitation settings, or there is none available (Joseph, 2017).

In South Africa, there are policies in place that service providers are supposed to adhere to, such as, The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which mandates access to healthcare for all people with disabilities (Hussey, MacLachlan & Mji, 2016). However, in South Africa, the challenges are accessibility to the facilities/services and transport. In addition, South Africa has its own National Rehabilitation Policy (NRP), which was developed and published in 2000, while a national report of 2014 revealed that 94% of persons with private medical aids were very satisfied with services/facilities, compared to only 60% using public care. South Africa's policies for good quality care are in place; however, the execution thereof could be improved (Hussey *et al.*, 2016). Therefore, it is important to investigate the mortality, as well as the living conditions and health statuses of patients in community, in order to inform community based services.

## **2.10. Prehospital/ acute care**

South Africa is the only country on the African continent with an organised, statutory system of pre-hospital care, and the National Healthcare Plan aims to ensure that, at least, basic life

support is available to all, within 20 minutes after injury (Goosen, Bowley, Degiannis & Plani, 2003). In Canada, research has established that surgery performed within 24 hours, in incomplete acute TSCI in the cervical, thoracic, or thoracolumbar spine, improves motor neurological recovery and reduces the length of hospital stay (Dvorak *et al.*, 2015). The pattern of trauma has changed completely in South Africa, with the majority of major trauma being due to gunshot-wounds, as well as a decline in stab-wounds (Goosen *et al.*, 2003), which is in line with the TSCI aetiology profile in the Cape Town Metropolitan area. According to the researcher, the bulk of trauma is managed in regional hospitals, with a surgeon on call, and urgently available; however, the problem with this scenario is there are very few district hospitals capable of receiving, and adequately managing, major trauma.

In 2006, a system was developed by the Cape Triage group, to assist with the process of sorting patients, according to medical need, in emergency units throughout South Africa. The colour system was used, with categories grouped and named in colours, as follows: red – immediate priority (resuscitation cases); orange – very urgent priority (potentially life/limb-threatening pathology); yellow – urgent priority (significant pathology); green – delayed priority (minor injuries/illness); and blue – dead (Gottschalk, Wood, DeVries, Wallis, Bruijns & Cape Triage Group, 2006).

## **2.11. Rehabilitation**

Rehabilitation is treatment that restores an individual to health. Its aim is to add years to life, by facilitating people with spinal cord injuries to function independently and creating conditions for social integration (Visser-Meily, Post, Schepers & Lindeman, 2005). In South Africa, rehabilitation, following injury, is in a dismal state in the public sector, with 25-30% of the acute care beds blocked, at any one stage, by patients awaiting transfer to rehabilitation facilities (Joseph *et al.*, 2017). The private sector displays the exact converse, with excellent acute and chronic facilities that abound (Goosen *et al.*, 2003). The Western Cape Rehabilitation Centre (WCRC), a rehabilitation centre for people with physical disabilities, is a specialised rehabilitation centre. It accepts appropriate referrals from all levels of health services, and patients can also refer themselves. Persons with SCIs receive specialized services, such as vocational rehabilitation, promotion in independence care, recreational activities, re-integration into society, provision, repair and maintenance of assistive devices, as well as work and home assessments (Western Cape Rehabilitation Centre, 2017).



## **2.12. Community based services**

According to the WHO, community based rehabilitation (CBR) was initiated following the Declaration of Alma-Ata International Conference on Primary Health Care, Alma-Ata, USSR, 6–12 September 1978 (2004), in an effort to enhance the quality of life for people with disabilities and their families, meet their basic needs, and ensure their inclusion and participation. The aim of community based services is mainly to assist those with TSCIs, as well as their families, as they transition toward a functional *new normal*, regarding mobility, and activities of daily living (ADLs), including community and social reintegration. In South Africa (Western Cape), the low employment rate and difficulties experienced with community reintegration, after SCIs, largely affect the environmental factors of participation, especially transport and education, in order to return to work (Maclachlan, 2012).

## **2.13. Deficit in Literature**

Although, there is dearth of information and research regarding SCIs in South Africa, the incidence of TSCIs and prevalence of secondary medical conditions, during acute care, in the province of the Western Cape, has been established by Joseph *et al.* (2015). This incidence study was only conducted in one municipality, in one province in South Africa, the Western Cape; therefore, the results cannot be generalized to the whole of South Africa, as the crime rate in each province varies. Consequently, it is essential that the incidence and aetiology of TSCIs for the entire nation of South Africa be explored, which however, is beyond the scope of this current study. In addition, no mortality data on persons with TSCIs currently exists in South Africa; therefore, the survival rate, as well as the functioning of patients in the SCI community, needs to be investigated, in-depth, in order to improve and strengthen the country's healthcare system. Ultimately, a better understanding of the reasons why people succumb prematurely, after an SCI, has become crucial.

## **2.14. Summary**

The mortality of TSCI patients can be prevented/managed by addressing modifiable factors, which challenges the system of care in South Africa. The mortality rates of common injuries, such as TSCIs, reveal the quality of care that countries provide to survivors with injuries. When these rates are well above the standardised mortality rates of able-bodied citizens, it is crucial to identify the factors that lead to the loss of life. These factors could be used to develop preventative strategies, with the aim of promoting healthy aging with SCIs. Although, there is

a grave need for preventative measures, the survival of individuals with these injuries needs to be determined, for the overall impact, before those preventative measures can be developed, and implemented effectively.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **3.1. Introduction**

In this chapter on the methodology, the researcher discusses the research setting, which is the province of the Western Cape, as well as the health services available in the area. In addition, the research design, which is a prospective, population-based design, is described, in detail. The study population and sampling are discussed, and the data collection procedure, as well as instrumentation used in this current study, are reviewed. Additionally, the variables in the assessment of factors related to mortality, grouped into dependent variables, independent variables, non-modifiable factors and modifiable factors, are explored. Finally, the data analysis procedure is presented, in detail, while the ethical considerations and ethical principles, related to research conducted on humans, as per the Helsinki Declaration, are explained.

#### **3.2. Research Setting**

The Western Cape Province is one of 9 provinces in South Africa, which is situated in the southern western part of the country. There are 30 municipalities in the Western Cape, divided into five rural districts and one metropolitan district, which is the City of Cape Town. This current study was conducted in the Province of the Western Cape, in the City of Cape Town metropolitan district. According to the last census in 2011, the City of Cape Town's population was 3.74 million people, with a population density of 1 530 people per square kilometre. The City of Cape Town's 2017 population is now estimated at 4 004 793 (City of Cape Town, 2017).

The metropolitan district consists of urban and peri-urban areas, and has one level 1 hospital with a specialised Spinal Cord Injury unit, Groote Schuur Hospital, working alongside Tygerberg Hospital, which is also a tertiary (level 1) hospital. Due to the limited resources at the specialised hospital, patients are seen on a referral basis, from the secondary hospitals, which is a major problem, as the quality of care is delayed (Joseph *et al.*, 2017). The Acute SCI unit admission criteria and priority scale, applied at Groote Schuur hospital, for the admission of patients for life saving treatment, is presented in Table 3.1 (Sothmann, Stander, Kruger & Dunn, 2015).

**Table 3.1: Acute Spinal cord injury admissions to ASCI Unit, priority table\***

P1	Incomplete acute SCI in need of urgent spinal cord decompression operation/ procedure.
P2	Acute SCI with unstable cervical spine fracture in need of spinal fusion operation.
P3	Acute SCI with unstable thoracic/lumbar spine fracture in need of spinal fusion operation.
P4	Acute SCI with SCI-related complication e.g. spinal shock, respiratory failure.
P5	Acute SCI with unstable fracture of the spine for conservative management in traction.
P6	Acute SCI for removal of the bullet.
P7	Acute SCI with stable fracture of the spine.
P8	Acute SCI, not fit for rehabilitation (e.g. infection or SCI-related complications).
P9	Stable post-acute SCI fit for rehabilitation.
P10	Stable post-acute SCI with sacral, ischial or trochanteric pressure ulcer, otherwise fit for rehabilitation.

\*Inclusion criteria: acute traumatic spinal cord injury; exclusion criteria: severe head injury, Glasgow Coma Score <13/15 or 9T/15, polytrauma.

Little is known about the chain-of-care for persons with SCIs, specifically, whether community-based rehabilitation services are offered. There are numerous primary healthcare facilities providing follow-up care to persons with health conditions. Rehabilitation is offered at the Western Cape Rehabilitation Centre (WCRC), which also follows a priority list, first treating those who have the most potential to benefit from high intensity rehabilitation (Western Cape Rehabilitation Centre, 2017). Regarding rehabilitation specifically, care provision during this period should address issues with community integration and return-work; however, the

extent to which these goals are addressed, and achieved, remains unknown. According to the 2016 City of Cape Town socio-economic profile, there are 81 fixed clinics, 26 mobile/satellite clinics, 42 community day centres, and 9 district hospitals situated within the City of Cape Town, with 0.26 ambulances available per 10 000 population(City of Cape Town, 2017)..



**Figure 3.1: The Cape Town Metro Municipality**

### **3.3. Research design**

A prospective, population-based research design was employed, and all persons who sustained a TSCI during a defined period, were included (Weinstein, Rothman & Sutton, 1998). This current project was a follow-up of a prospective study, aimed at determining the incidence and aetiology of persons with TSCIs, for a 1-year period, from 15 September 2013 to 14 September 2014 (Joseph *et al.*, 2015). The aim of this current study was to follow up on all patients, who were admitted and treated at two of the Western Cape's tertiary hospitals, namely, Tygerberg and Groote Schuur Hospital. The participants were monitored back into their communities, to

investigate their survival and health status, four years post-discharge. This current project specifically reports on the four year mortality, following TSCIs. The researcher selected this research design, as the validity of the findings would be relevant to the entire source population, which is the Cape Metropolitan area. The findings, however, not generalizable to other areas of the Western Cape, or South Africa at large, due to possible differences in aetiological profiles and systems of care. In addition, a cross-sectional design was used to determine the period prevalence of secondary medical complications, during the four year follow-up phase, using a standardised, valid and reliable survey (Weinstein *et al.*, 1998).

### **3.4. Study population**

The study population comprised all the respondents with TSCIs, who were enrolled for the incidence study, which was conducted in 2013/2014 (Joseph *et al.*, 2015). The study population, therefore, consisted of 145 consenting participants, of which 124 were male, and 21 female.

### **3.5. Sampling**

#### **3.5.1. Type of Sampling**

An inclusive sampling strategy was adopted, in which all those in the initial incidence study, would be eligible to participate in the four-year mortality study.

#### **3.5.2. Sample Size and Inclusion Criteria**

All the respondents with TSCIs (145), who were recruited and participated in the 2013/2014 study (Joseph *et al.*, 2015), and were living in the City of Cape Town 4 years post-injury, were invited to participate in this current study. The same inclusion criteria of the incidence and aetiology of traumatic spinal cord injuries study in Cape Town were used, namely: The prospective respondent had to (1) have a confirmed acute traumatic spinal cord, or cauda equina lesion; (2) be aged 18 or older at the time of injury, (3) be a resident of the country and of the catchment area; (4) have provided informed consent; and (5) be the immediate family member(s) of deceased patients. No specific exclusion criteria applied in the follow up study. The number of respondents, who consented to participate in the survey is presented in Table 3.2.

### **3.6. Data collection procedure**

All the eligible respondents (145) were initially contacted telephonically, and given an option of selecting the mode of data collection; either telephonically with a researcher-administered questionnaire, or in-person with a self-administered questionnaire. The respondents, who chose to be surveyed via telephone, were thoroughly informed about the study, after which, verbal consent was sought from them. In addition, they were informed that their consent statement would be recorded, by an audio-recorder, at the start of data collection process, in order to retain proof of their willing participation. Alternatively, they were informed of an option to receive the information sheet (Appendices 2-7) and consent form (Appendices 11-13) via registered mail, which had to be returned prior to the telephonic survey.

After being thoroughly informed about the study, written consent was sought from those who opted for the in-person survey, prior to the start of data collection. For the patients who had deceased, a close family member, or former caretaker, was asked to partake in the study, who, upon consent (using the two options described above), was only requested to provide verbal disclosure of the cause of death, as stated on the death certificate. The questionnaire took approximately 45 minutes to complete. In cases where the respondents could not complete the questionnaire in one sitting, especially during the telephonic survey, they were allowed to complete the rest of the items, within seven days, in order to ensure that their health status did not change much, between calls.

In order to establish the generalisability of the findings of this current study, to the immediate source population, the researcher accounted for every non-responder, only recording their sex, age, education, and level of lesion, which was available from the baseline data collected during 2013/2014. Details of the non-responders, namely, those lost to the follow-up study, are presented in Table 3.2. The results indicate that the non-responders did not differ from the responders, regarding gender, age, level and completeness of injury, and injury aetiology, implying that those who were lost to the follow-up study, were most likely random, and not systematic.

**Table 3.2: Non-response data: Responders vs non-responders**

NON-RESPONSE ANALYSIS: RESPONDERS VS NON-RESPONDERS					
Variable	Responders (n)	Non-Responders (n)	P-value		
<b>Gender</b>			0.225		
Male	63	62			
Female	13	7			
<b>Age* Mean(SD)</b>	36.2(14.5)	38.1(12.9)	0.427		
<b>Level of injury</b>			0.430		
Paraplegia	38	39			
Tetraplegia	38	30			
<b>Completeness of injury</b>			0.298		
Complete	34	35			
Incomplete	42	34			
<b>Etiology</b>			0.385		
Accident during sport or leisure activities	1	3			
Injury due to violence	44	45			
Traffic accident	23	14			
Fall from lees that 1 metre	8	6			
Fall from more than 1 metre	0	1			

\*The students test was used to assess the differences in age, otherwise Chi square or Fischer's excel test was used. Concerning the non-responders, the 11 accounted for initially as part of the mortality objective were considered as "non responders" for the subsequent objectives focusing on health status.

### 3.7. Instrumentation

The International SCI (InSCI) community survey was used as the data collection instrument. The InSCI survey is a WHO endorsed initiative, which is aimed at the learning health system for SCI, by comparing functioning data in a worldwide context (WHO, 2012). The survey was developed against the International Classification of Functioning, Disability and Health (ICF) background, which describes functioning and disability as a complex interaction between an individual's health condition and contextual factors (WHO, 2012). The InSCI survey consists of many standardized outcome measures, covering different functioning topics, and spanning the entire spectrum of the ICF (WHO, 2012). The specific instruments are described below, along with its psychometric properties. The questionnaire was translated into Afrikaans and IsiXhosa, and thereafter, the translated versions were tested for face validity, using ten individuals with long-term SCIs.

### 3.7.1. Demographic and mortality items

The InSCI survey captures a range of demographic (gender, age, marital status), socio-economic (education, employment, income) and other personal factors (lifestyle, confidence, independence, major adverse life event). The variables are used for explanatory purposes during analysis. Regarding mortality, this data were gathered from a reliable source (primary caregiver of the deceased). Data on date and cause of death was gathered via verbal autopsy.

### 3.7.2. Outcome measures

The Spinal Cord Injury Secondary Health Conditions Scale (SCI-SCS) was used to determine the period prevalence of selected complications (Kalpakjian *et al.*, 2007). The scale presents with optimal reliability (test-retest reliability ranged from 0.569 to 0.805) and validity (Kalpakjian *et al.*, 2007). The following secondary medical complications are included in the scale: pressure ulcers; injury caused by loss of sensations; muscle spasms contractures; heterotopic bone ossification; diabetes mellitus; bladder dysfunction; bowel dysfunction; urinary tract infection; sexual dysfunction; autonomic dysreflexia; postural hypotension; circulatory problems; respiratory problems; chronic pain; as well as joint and muscle pains. Each complication is scored on a Likert scale ranging from 1 (indicating no problem), to 5 (indicating major problem). For the analysis and presentation in this current study, the Likert scale was collapsed into two categories only, namely, no problem vs. some problem. However, the researcher was not concerned about the severity of the problem, but rather whether the problem was present during the last three months or not.

### 3.7.3. Variables in the assessment of factors related to mortality

#### 3.7.3.1. *Dependent variable*

Death at the time of data collection (four years after injury) was considered the main dependent outcome.

#### 3.7.3.2. *Independent variables*

Independent variables are exposure variables, which could be related to the dependent outcome. The non-modifiable and modifiable independent variables selected for this study are described below.



- *Non-modifiable factors*

Age, gender, level of injury, completeness of injury, aetiology, acute secondary medical complications were classified/categorised as non-modifiable factors, as they are risk factors that cannot be changed. Gender was categorised into males and females, level of injury dichotomised as paraplegia and tetraplegia, and completeness of injury was based on whether the person/s had complete or incomplete injuries. Aetiology was grouped into the following classes: sports/leisure activities; assault; transport; falls less than 1 metre and falls more than 1 metre. The presence of acute secondary medical complications was also analysed as a non-modifiable factor at four years after injury.

- *Modifiable factors*

Spinal surgery, intermediate hospitalization, education, length of hospital stay, secondary medical complications were classified/categorised as modifiable factors, as they are risk factors that can be changed. The researcher analysed the persons who received spinal surgery/or not, intermediate hospitalization, and the number of days spent in hospital on acute admission. Education was grouped into whether the participants had less than 12 years education; no secondary schooling; and more than 12 years education. Secondary medical complications were analysed as presence of the following: sleeping problems, bowel dysfunction, UTIs, bladder dysfunction, sexual dysfunction, contractures, muscle spasms, pressure sores, respiratory problems, Injury due to loss of sensation, circulatory problems, autonomic dysreflexia, postural hypotension and pain, as indicated in the InSCI survey.

### **3.8. Data Analysis**

Data were captured on an Excel spreadsheet, summarized, as well as visualized, and subsequently, transferred to the SPSS for analysis. Respondent and injury characteristics were displayed, using descriptive statistics, while inferential statistics were used to determine the differences between the responders and non-responders. For the mortality rate estimation, the

standardized mortality ratio (SMR) was initially considered, in order to determine the risk associated with succumbing prematurely to TSCI, compared with the general population.

However, the absolute rate, expressed as a percentage of those enrolled in this current study, was presented due to the lack of sufficient numbers in each age and gender strata. Thereafter, binary logistic regressions were computed to determine factors that significantly relate to mortality (objective 2) and the development of secondary medical complications (objective 4). All factors were initially assessed in binary logistic regression models with the alpha level set at 0.05. Data were presented as odds ratios (ORs) with 95% confidence intervals (CIs).

### **3.9. Ethical Considerations**

Ethical clearance was obtained from the University's Research Ethics Committee (Ethics reference number BM17/6/11 – Appendix 1). All the respondents in the established cohort were contacted telephonically and invited to participate in the follow up study. All the information about the study was made available, and all procedures explained, after which the prospective respondents were asked whether they would formally consent to their involvement in this current study, or decline. Subsequently, the prospective respondents were given two options to complete the extensive survey; as a telephonic survey, with the questionnaire administered by the researcher, or as a face-to-face survey, with a self-administered questionnaire. Those who chose the face-to-face survey were required to provide signed, informed consent, prior to data collection (before completing the questionnaire). The others who chose the telephonic survey were asked to sign an informed consent form, which was sent to their current address, with a prepaid postal mail envelope, for the purpose of returning the consent form. Alternatively, their consent statement was secured, using an audio-recorder, prior to the start of data collection process. All respondent identification data were replaced by a unique code, to which no unauthorized persons had access, for confidentiality optimisation. The raw data were stored in a locked filing cabinet situated in the principal investigator's (supervisors') office. Subsequently, the data set was captured and stored on a password protected computer. Pseudonyms will be used in subsequent articles, should the need arise to isolate a mortality case.

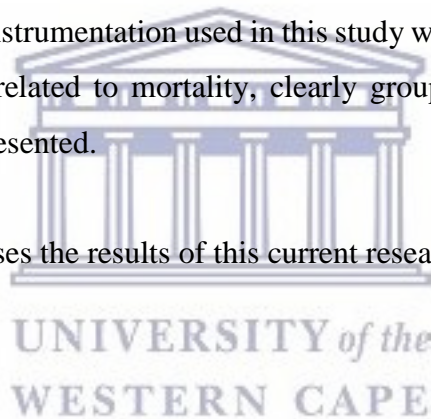
Due to the sensitive nature of the data, especially with families who had lost loved ones to SCIs, as well as those who had provided the cause of death information, obtained from death certificates, information was handled with additional caution. All documents were kept in a

locked cabinet of the primary investigator, and will be discarded in 5 years' time. In the event of harm being caused, or should the respondents have experienced any problems that could not be resolved by the researcher and study supervisor, an appropriate referral was made. Finally, the respondents had the right to withdraw from the study at any time, without negative consequences. The results of this current study will be made available to the Western Cape Department of Health, and a layman's version will be made available to the respondents. In addition, the results will be published in a peer reviewed journal, in order to address the lack of knowledge.

### **3.10. Summary**

The methods employed to conduct this current study were discussed, as well as the research setting and the health services, offered in the research area. A prospective, population-based design was used, while the study population and sampling were clearly defined. The data collection procedure and the instrumentation used in this study was reviewed, and the variables in the assessment of factors related to mortality, clearly grouped and defined. Finally, the ethical considerations were presented.

The following chapter comprises the results of this current research study.



## CHAPTER FOUR

### FINDINGS

#### 4.1. Introduction

In this chapter, the researcher discusses the results of the captured data analysis. The participants' injury characteristics, four year mortality after injury, factors related to mortality at four years, the prevalence of secondary medical complications at four years, using a 3 month window period, as well as factors related to the development of medical complications are presented in the following text and accompanying tables.

#### 4.2. Respondents' injury characteristics

The demographic and injury characteristics, as well as the prevalence of acute secondary medical complications of the 87 persons, who were available for follow up in the 4 years post-SCI were analysed descriptively (see Table 4.1). A total number of 55 persons (63%) were alive and completed the full survey, 21 persons (24%) were deceased by the time of the 4-years-post-injury inquiry, and 11 people (13%) were classified as alive, but did not participate in the follow up study. The majority of the respondents available for follow up were males (n=72, 82.7%). A large number of the respondents were between the ages of 18-30 (n=37; 42.5%), followed by those in the age range of 31-45 (n=30; 34.4%), and those persons older than 60 years (n=7; 8%). The most common cause of injury was assault, followed by transport injuries and the least was sports-related/ leisure activities (n=1, 1.1%). A total number of 47 persons (54%) received spinal surgery and 40 (46%) did not receive spinal surgery on admission. On acute admission, 48 people (55%) had acute secondary medical complications. Table 4.1 illustrates participants' characteristics.

**Table 4.1: Participants injury characteristics**

CHARACTERISTICS	RESPONDENTS	%
<b>Total (n, %)</b>	<b>87</b>	<b>100</b>
<b>Gender (n, %)</b>		
Female	15	17.2
Male	72	82.7
<b>Age*(n, %)</b>		
18-30	37	42.5
31-45	30	34.4
45-60	13	14.9
>60	7	8
<b>Participants (n, %)</b>		
Alive and completed survey	55	63
Dead	21	24
Missing (Alive but not reachable)	11	13
<b>Level of injury (n, %)</b>		
Tetraplegia	45	52
Paraplegia	42	48
<b>Completeness of injury (n, %)</b>		
Complete	37	43
Incomplete	50	57
<b>Aetiology (n, %)</b>		
Sport/leisure	1	1.1
Assault	53	60.9
Transport	24	27.5
Falls	9	10.3
<b>Spinal Surgery (n, %)</b>		
Received Spinal Surgery	47	54
Did not receive any surgery	40	46
<b>Secondary Medical Complications on admission (n, %)</b>		
Yes	48	55
No	39	45
<b>Prevalence of pressure ulcers (n, %)</b>		
Yes	25	28.9
No	62	71.1
<b>Pulmonary complications (n, %)</b>		
Yes	21	24.1
No	66	78.9

Associated injuries (n, %)		
No	30	34.5
Yes	57	65.5

\*Age as of 30 June 2017 – for four year follow up

### 4.3. Mortality four years after injury

Out of the 87 participants with TSCI included in this study, 24% (n=21) had died within the previous four years. Of these, the majority (76%) were males. The main cause of death reported was septicaemia (n=7; 33%), followed by an unknown cause of death (n=7; 33%), death due to pressure ulcers (n=5; 24%), and the least common cause reported as death classified as other (n=2; 9.5%, stomach cancer, natural causes).

#### 4.3.1. Factors related to mortality at four years

For the assessment of factors related to death, both modifiable and non-modifiable factors were considered. Non-modifiable factors that were analysed included gender, level of injury, completeness of injury, age and aetiology. The univariate logistic regression results, in the table below, reveal that the only significant non-modifiable factors related to death were completeness of injury, where persons with an incomplete spinal cord injury were four times less likely to die (OR: 0.2; 95% confidence interval (CI): 0.07-0.58)  $p=0.003$ . For aetiology, those with transport related injuries were at almost nine times less risk of death in comparison to falls (OR: 0.11; 95%CI: 0.01-0.76). The following non-modifiable factors – age, gender, level of injury – had no significant association with death.

For modifiable factors, only those who had acute secondary medical complications on acute admission, had one and a half (OR: 2.5) more risks of death; however, only a trend was noted ( $p=0.091$ ). Similarly, those with pulmonary complications had 150% more risk, also not significant, but close to significance with  $p=0.092$ . Spinal surgery, pressure ulcer, length of hospital stay and education had no significant association with death.

**Table 4.2: Factors related to four-year mortality**

<b>Variables</b>	<b>OR (95%CI)</b>	<b>P-value</b>
<b>Non-modifiable factors</b>		
<b>Gender</b>		0.364
Female	1.75(0.52-5.86)	
Male	1.00(reference)	
<b>Level of injury</b>		0.945
Tetraplegia	0.96 (0.36-2.58)	
Paraplegia	1.00 (reference)	
<b>Completeness of injury<sup>a</sup></b>		<b>0.003</b>
Incomplete	0.2 (0.07-0.58)	
Complete	1.00 (reference)	
<b>Age</b>		0.628
18-30	1.00 (reference)	
≥31	1.01(0.97-1.04)	
<b>Aetiology</b>		
Assault	0.49 (0.12-2.09)	0.338
Transport	0.11(0.01-0.76)	<b>0.026</b>
Falls	1.00 (reference)	
<b>Modifiable factors</b>		
<b>Spinal Surgery</b>		0.862
Yes	0.91 (0.34-2.45)	
No	1.00 (reference)	
<b>Acute medical complications</b>		0.091
Yes	2.5 (0.86-7.23)	
No	1.00 (reference)	
<b>Pressure Ulcers</b>		0.985
Yes	0.98 (0.33-2.93)	
No	1.00 (reference)	
<b>Pulmonary complications</b>		0.092
Yes	2.50 (0.86-7.31)	
No	1.00 (reference)	
<b>Education</b>		0.522
Less than 12 years/ No schooling	1.00 (reference)	
Secondary and more than 12 years	0.68(0.22-2.18)	
<b>Length of hospital stay (Continuous)</b>	1.01 (0.98-1.02)	0.611

<sup>a</sup> Completeness of injury was determined using the ASIA classification. We dichotomized completeness based on motor function; thus, motor complete by combining ASIA A and B (ASIA A | B) and motor incomplete by aggregating ASIA C and D (ASIA C | D). OR=Odds ratio; CI=Confidence interval.

#### **4.4. Prevalence of secondary medical complications at four years**

The prevalence of secondary medical complications was based on those who were alive at four years after injury (N=55). An alarming 69% of those alive at four years after injury, had a medical complication, with only 31% being free of secondary medical complications. The most common complications were pain, which was present in 80% of the sample, muscle spasms in 76.4%, sleeping problems in 69% and autonomic dysreflexia in 52.7%. The least common secondary medical complications were pressure sores, present in 18.2%, respiratory problems (14.5%) and injury due to loss of sensation (7.3%).





**Table 4.3: Secondary medical complications the last three months**

<b>Presence of medical complication (n, %)</b>	<b>55</b>	<b>100</b>
No	17	31
Yes	38	69
<b>Sleeping problems (n, %)</b>		
No	24	43.6
Yes	31	56.4
<b>Bowel dysfunction (n, %)</b>		
No	32	58.2
Yes	23	41.8
<b>UTI's (n, %)</b>		
No	40	72.7
Yes	15	27.3
<b>Bladder dysfunction (n, %)</b>		
No	31	56.4
Yes	24	43.6
<b>Sexual dysfunction (n, %)</b>		
No	34	61.8
Yes	21	38.2
<b>Contractures (n, %)</b>		
No	33	60
Yes	22	40
<b>Muscle spasms (n, %)</b>		
No	13	23.6
Yes	42	76.4
<b>Pressure sores (n, %)</b>		
No	45	81.8
Yes	10	18.2
<b>Respiratory problems (n, %)</b>		
No	47	85.5
Yes	8	14.5
<b>Injury due to loss of sensation (n, %)</b>		
No	51	92.7
Yes	4	7.3
<b>Circulatory problems (n, %)</b>		
No	30	54.5
Yes	25	45.5
<b>Autonomic dysreflexia (n, %)</b>		
No	26	47.3
Yes	29	52.7
<b>Postural hypotension (n, %)</b>		
No	35	63.6
Yes	20	36.4
<b>Pain (n, %)</b>		
No	11	20
Yes	44	80

#### **4.5. Factors related to developing medical complication**

During the investigation of factors related to the development of medical complication(s), both modifiable and non-modifiable factors were considered. Concerning non-modifiable factors, completeness of injury was significantly associated with the development of a secondary medical complication, where those with incomplete injuries were four times (OR: 0.18; 95%CI: 0.05-0.61) less likely to develop a complication. Gender, level of injury, age, aetiology and acute medical complications did not have a significant association with the development of a secondary medical complication, four years post-injury. For modifiable factors, only a longer length of hospital stay in the acute phase, led to the higher likelihood of developing a secondary medical complication at four years after injury. In addition, spinal surgery and education had no significant association with the development of secondary medical complications, 4 years post injury.



**Table 4.4: Factors related to developing a medical complication within the last 3 months**

<b>Variables</b>	<b>OR (95%CI)</b>	<b>P-value</b>
<b>Non-modifiable factors</b>		
<b>Gender</b>		0.552
Female	0.63 (0.13-2.92)	
Male	1.00(reference)	
<b>Level of injury</b>		0.898
Tetraplegia	0.93 (0.32-2.69)	
Paraplegia	1.00 (reference)	
<b>Completeness of injury</b>		<b>0.006</b>
Incomplete	0.18(0.05-0.61)	
Complete	1.00 (reference)	
<b>Age</b>		0.372
18-30	1.00 (reference)	
≥31	0.98(0.94-1.02)	
<b>Aetiology</b>		
Assault	1.00 (reference)	
Transport	0.51 (0.16-1.61)	0.251
Falls	0.19(0.19-1.92)	0.160
<b>Acute medical complications</b>		0.091
Yes	2.5 (0.86-7.23)	
No	1.00 (reference)	
<b>Modifiable factors</b>		
<b>Spinal Surgery</b>		0.145
Yes	0.45(0.15-1.32)	
No	1.00 (reference)	
<b>Education</b>		0.770
Less than 12 years/ No schooling	1.00 (reference)	
Secondary and more than 12 years	0.84 (0.27-2.62)	
<b>Length of hospital stay (Continuous)</b>	1.04 (1.01-1.07)	<b>0.020</b>

#### **4.6. Summary of results**

The mortality rate was 24% four years post injury. The significant factors related to mortality, four years post injury, were persons with complete spinal cord injuries, with injuries due to falls. Concerning medical complications at four years, 69% of patients had at least one medical complication. The most common secondary medical complications at four years after injury were pain, muscle spasms, sleeping problems and autonomic dysreflexia, while the least common secondary medical complications were pressure sores, respiratory problems and injury due to loss of sensation. The only factors related to the development of a medical complication, four years post injury, were completeness of injury, as well as having a longer length of acute hospitalisation.



## CHAPTER FIVE

### OVERVIEW AND DISCUSSION

#### 5.1. Introduction

In this chapter, the researcher provides a detailed overview and discussion of the main findings. The comparisons concerning mortality and secondary medical complications are presented, using international literature, specifically, comparing the current findings with other African countries, due to the similarities in healthcare systems. The findings of this current study are linked to the main theoretical framework of the study, Krause's theoretical risk and prevention model.

#### 5.2. Study main findings

The mortality rate, four years post injury, was 24%, with a total number of 55 persons (63%), identified as alive, the majority (76%) being males, having completed the InSCI survey. The leading cause of reported deaths was septicaemia, with the lowest cause being deaths due to other natural causes. The researcher identified two non-modifiable factors related to death, namely, persons with complete spinal cord injuries, and persons with injuries due to falls.

Concerning the secondary medical complications at four years, 69% of the respondents had, at least, one secondary medical complication, and 31% had none. The most common secondary medical complications at four years after injury were pain, muscle spasms, sleeping problems and autonomic dysreflexia, while the least common ones were pressure sores, respiratory problems and injury due to loss of sensation. The only identified factors related to developing a secondary medical complication, four years post injury, were completeness of injury and an extended length of acute hospitalisation.

Regarding factors related to developing a/any medical complications, both modifiable and non-modifiable factors were considered, using univariate logistic regression analysis. The findings revealed that persons with acute secondary medical complications were 2.5 times (95% CI: 0.86-7.23) more likely to develop a/any medical complication, four years post injury. The level of injury had no significance to the development of a secondary medical complication, while

completeness of injury had a significant association with the development of a secondary medical complication, as well as for mortality in this current study

### **5.3. Mortality in focus**

The results of this current study revealed a mortality rate of 24.2%, which was low compared to what was predicted, but still high, when compared to other countries. The high survival rates were in contexts where specialised systems existed. In certain first-world countries, approximately 80% of people with diagnosed SCI, survive at least 10 years after injury (Furlan *et al.*, 2011). South Africa is challenged with a high unemployment rate, increasing crime, as a result, violence and violence-related injuries are the subsequent leading causes of mortality and lost disability-adjusted life years (Seedat *et al.*, 2009). A one-year-post-injury prospective, population-based study revealed a 20% mortality rate in Thessaloniki, Greece, while no deaths occurred in Stockholm, Sweden, during that period. The mortality rate after acute TSCI was nearly 20% in Thessaloniki, and 0% in Stockholm, while the factors associated with mortality, were a higher age, and the presence of comorbid spinal disorders, as well as the inefficient transfer logistics, initially missed spinal instability, and unsuccessfully treated complications (Divanoglou & Levi 2009). The mortality rate in Thessaloniki was higher, in comparison to Stockholm, and the factor leading to such discrepancies was noted to be the differences in the approaches to care, with Greece following a non-specialised approach, and Sweden a specialised approach (Divanoglou & Levi 2009).

A one-year acute follow-up descriptive study was conducted in Botswana, including people with traumatic spinal cord injury, and revealed a mortality rate of 20% (Löfvenmark *et al.* 2015), which was lower than the mortality rate of 24% observed in this current study. The difference in the follow-up time between the two studies could have contributed to this dissonance in mortality rate. The lower than expected mortality rate observed in this current study could be due to the loss to follow-up (n=69; 48%), indicating that this rate underestimates deaths after TSCI in South Africa. Therefore, future studies are required with a shorter follow up period, for example, one year post TSCI, to assess the initial impact of the health system on survival. The researcher found no evidence of other studies, which were conducted internationally, or in neighbouring African countries, with similar objectives and a similar follow-up period, as used in this current study, which interrogates whether the mortality rate is higher or lower. However, the mortality rate could be compared to that of the able-bodied

population, in order to assess the impact of the disease or injury, in this case TSCI. The 24% mortality in this cohort is indeed higher than the general population of South Africa, over a four year period. The main causes of death, based on interviews with carer/family members, or hospital records, were listed as pressure ulcers (24%), septicaemia (33%), unknown reasons (33%), and other causes of death (9.5%), for example, stomach cancer and natural causes.

The risk factor, as identified in this study, was septicaemia. In a study comparing mortality in Greece and Sweden, the leading causes of death was identified as, higher age and the presence of comorbid spinal disorders. Botswana, a neighbouring African country, reported high mortality/leading cause of death among the tetraplegic spinal cord injured persons (Löfvenmark *et al.* 2015). The results are very different to those of this current study; however, the researcher does not attempt to conclude that specific complications led to the mortality of those surviving, thereby not inferring causality, but rather that systems should be implemented to address factors observed to be associated with the risk of death and well-being.

In Australia, the leading cause of death was related to the level of lesions, and the severity of injury, with a Standard Mortality Ratio (SMR) of 2.4 (Yeo *et al.*, 1998). In the United States of America, mortality rates in the SCI community increased by 33% from 1993 to 1998, where the leading cause of death was reported to be respiratory diseases. A cross-sectional study in Norway reported a SMR of 1.8 for men and 4.9 for women, while the leading cause of death was pneumonia/influenza (Lidal *et al.*, 2007). A retrospective study in Denmark reported septicaemia and pneumonia as the leading causes of death in the SCI community (Hartkopp *et al.*, 1997).

As established by previous researchers, South Africa has a different etiologic profile to that of the world (Joseph *et al.*, 2015); therefore, a higher mortality rate was predicted. A high percentage of those who had demised had secondary complications in the acute phase, as well as those with complete injuries. The non-modifiable risk indicators identified in this current study, using univariate logistic regression analysis, revealed that completeness of injury, and persons with an incomplete spinal injury were four times less likely to succumb (OR: 0.2). Additionally, those with transport related injuries had almost nine times (OR: 0.11) less risk of mortality, in comparison to falls. The strongest modifiable factors related to mortality was observed to be those with acute secondary medical complications on acute admission, and those

with pulmonary complications; however, this was not significant at the conventional alpha level of 0.05.

According to Krause's model, injuries due to violence, predominantly gun-shots, did not result in significantly more fatalities. Concerning other aetiologies, environmental factors, such as spinal surgery, length of hospital stay and education, also did not result in more fatalities. The reason for this lack of association between assault-related injuries and mortality is not known. Further investigations need to be made to identify why those with falls injuries were more likely to succumb within four years. Importantly, through Krause's model, the potential need to target those with acute medical complications was identified, with the aim of improving their chances of survival.

With the surviving respondents, the prevalence of one or more secondary medical complications was determined, using the InSCI survey, which examined secondary medical complications, which the respondents were experiencing, or had experienced over the preceding three months. An alarming result of 69% had a medical complication or more, with a mere 31% being free of secondary medical complications. Specifically, 56% reported problems falling asleep, or sleeping through the night and waking up early, while 43.6% of patients had no problems at all.

Additionally, 58% participants had no problems with bowel functioning, and 42% reported problems with bowel functioning, such as diarrhoea, stool incontinence and constipation. In London, a study examined bowel function, which was identified as a major physical and psychological problem in SCI patients. Subsequently, the study identified that nausea, diarrhoea, constipation, and faecal incontinence were all much more common ( $p < 0.0001$ ) after SCI. Most of the patients (95%) required at least one therapeutic method to initiate defaecation (Glickman & Kamm, 1996).

In addition, 73% had no urinary tract infections, while 27% of the respondents reported problems with their urinary tract system, kidneys or bladder infection. A number of persons (38.2%) complained of sexual dysfunction related problems, while 62.8% reported no problems with their sexual dysfunction. Others expressed never having attempted, or finding ways to deal with it; therefore, although it was problematic biologically, it was not a problem for them at four years post injury, as they had adjusted.



A percentage of 40% reported having fixed deformities, and contractures in one or more joints, while 60% had no contractures at all. A high number of 76.4% of the respondents expressed problems with muscle spasms, some even complaining that it restricted them from performing their activities of daily living (ADLs), as required. In the acute phase, 29.8% of the respondents complained of pressure sores, and in the follow-up study, some reported having had pressure sores in the past, but not presently, or in the preceding 3 months, while 14.5% reported respiratory problems, such as symptoms of respiratory infections, or problems, including difficulty to breath and increased secretions. The findings on the acute study were similar to that of the worldwide, most common secondary complications (Joseph & Nilsson Wikmar, 2016); however the new findings on the four-year follow up were different, as pain, muscle spasms, sleeping problems and autonomic dysreflexia were identified as the most common secondary medical complications, and the least common secondary medical complications were pressure sores and respiratory problems. A number of persons (36.4%) reported postural hypotension problems, while the remaining 64.6% had no problems at all. A high 80% of respondents reported pain daily, or intermittent pain in their daily lives.

According to Krause's theoretical model of mortality for SCI, to be successful in the prevention of mortality and secondary medical complications, and to promote longevity, the risk factors causing their occurrence must be understood, and strategies to address these risk factors should be developed (Krause *et al.*, 2013). This current study, therefore, is an attempt at identifying the secondary medical complications, in order for them to be addressed in people living with TSCI in the Republic of South Africa. The model groups factors that predict mortality and secondary health conditions into 4 levels, according to type and proximity to mortality, which include, demographic and disability factors, psychological and socio-environmental factors, an additional path from socio-environmental factors to health outcomes, and a direct path from behaviours to mortality, to account for mortality related to intentional injuries and homicide (Krause & Saunders, 2012). In this current study, particular focus is on demographic/injury factors and secondary conditions. The demographic factors had no direct impact on mortality, and secondary conditions were identified as predictors of mortality. Concerning the injury factors, those with complete injuries, as well as those with falls-related injuries, were at most risk. There is a need for a better understanding of why those with complete injuries and falls injuries succumb sooner.

#### **5.4. Summary**

In this chapter, the researcher reviewed the main findings of this current study, and further reflected, as well as reviewed the relevance of the conceptual model in the findings. The mortality in focus was discussed in detail. The literature was reviewed and comparisons made to the findings, specifically, the most common secondary medical complications, based on literature. The application of Krause's model of mortality and secondary medical conditions allowed the identification of risk factors that should be taken into account in South Africa, specifically, septicaemia and pressure ulcers.



## CHAPTER SIX

### CONCLUSION, RECOMMENDATIONS AND LIMITATIONS

#### 6.1. Conclusion

Concerning the first objective, to determine the mortality rate four years after a TSCI, the death rate was observed to be 24%, which is evident that people succumb because of the injury. The different etiologic profile, compared to other countries, and the high mortality of TSCIs in the Western Cape, South Africa, clearly indicates that improvements in medical care and more rehabilitation facilities, may decrease mortality, due to modifiable factors of TSCIs in South Africa. For the second objective, to determine risk indicators for mortality of persons with TSCIs four years after injury, the only significant non-modifiable factor related to mortality was completeness of injury, where persons with an incomplete spinal cord injury were four times less at risk of succumbing, while for aetiology, those with transport related injuries were nine times less at risk of mortality, in comparison to falls related injuries.

Regarding the third objective, to determine the prevalence of secondary medical complications, four years after TSCIs, using a three-month window period, it was observed that secondary complications were not absent, instead, they were diverse, implying that specialised services should be available to address these complications, throughout life with SCIs. Those with complete lesions, as well as injuries due to falls, should be monitored more carefully, in order to optimise their recovery and livelihood. For the fourth objective, to determine the association between disease-related factors and the development of secondary medical complications at a four year follow-up, completeness of injury was highly significant in the development of a secondary medical complication, where those with incomplete injuries were four less likely to develop a secondary medical complication. The longer length of hospital stay in the acute phase, led to a higher likelihood of developing a secondary medical complication at four years after injury. This relationship should be explored further.

#### 6.2. Recommendations

- Implement annual follow-up systems to monitor the patient's progress, as well as a specialized record-keeping system to track patients, when they are discharged from the

tertiary hospitals to day hospitals/change provinces, to address problems as they occur in the course of life of those with spinal cord injury.

- Consider the development of a helpline, to assist people with information to treat and prevent modifiable secondary medical complications in South Africa.
- Consider the implementation of a regional registry to track all persons with SCIs, as well as to study the unmet needs of individuals, aimed at motivating the appropriate allocation of resources.
- Extend the study population to rural areas, as well as other provinces, to make it more representative of the entire population across the country.

### **6.3. Limitations**

- The high loss to follow up percentage was majorly affected by the lack of safety, which was a major risk, as many of the areas the respondents emanated from were in the Cape Flats of the Western Cape, affected by high violence/crime-related activities.
- The changed addresses and incorrect addresses issued on acute admission made the follow-up extremely difficult.
- The loss of contact with the primary caregiver, no follow-up addresses, as contact details were not available on the respondents' records.
- Over the 4-year-follow-up, the respondents changed contact details, their contact number no longer existed, or they had lost contact with people, whose number/s were saved as the next of kin person on admission records. This loss of contact with primary givers made follow-up difficult.
- The use of a subjective questionnaire, although validated and reliable, only reflected the subjective feedback on how the respondents experienced the secondary medical complications.
- The follow up rate was rather low. A large proportion, 48%, was unaccounted for. Therefore, the researcher is of the opinion that the mortality rate observed was an underestimation of the true impact of TSCIs in South Africa.
- Data on the severity of secondary medical complications, as well as the reasons why survivors of TSCI experience them, were not presented.

- Respondents with TSCIs, who had received private medical care, were not included in this current study. Therefore, the findings of this study are mainly applicable to those receiving public-funded care.



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## APPENDICES

### Appendix 1: Ethics Clearance letter



#### OFFICE OF THE DIRECTOR: RESEARCH RESEARCH AND INNOVATION DIVISION

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16 August 2017

Ms V Madasa  
Physiotherapy  
Faculty of Community and Health Sciences

**Ethics Reference Number:** BM17/6/11

**Project Title:** Survival and secondary medical conditions of persons with traumatic spinal cord injury in South Africa.

**Approval Period:** 15 August 2017 – 15 August 2018

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

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

**Please remember to submit a progress report in good time for annual renewal.**

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

A handwritten signature in black ink, appearing to read 'Josias'.

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

**PROVISIONAL REC NUMBER -130416-050**

## Appendix 2: English Information Sheet for Carers



# UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 71 614 2879

E-mail: 29272828@myuwc.ac.za

## INFORMATION SHEET FOR CARERS

**Project Title: Survival and secondary medical complications of persons with traumatic spinal cord injury in South Africa**

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

This is a research project being conducted by Vuyolwethu Madasa at the University of the Western Cape. We are inviting you to participate in this research project because you are one of the carers/ family members that took care of the patients that were part on the initial study that looked at the cause of traumatic spinal cord injury (TSCI) in South Africa in 2013/2014. The purpose of this research project is to better understand causes of death following TSCI four years after injury. The goal is to assist with the strengthening of South Africa's health system.

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

You will only be asked to report on the date and cause of death of the person you cared for. No further information will be required.

### **Would my participation in this study be kept confidential?**

We will do our best to keep your personal information confidential. To help protect your confidentiality, all information gathered will be stored in a locked filing cabinet. No unauthorised parties will have access to your information. Names of participants will be replaced by a unique study code which will be used throughout the study. In the event of writing a report or article, your identity will be protected to the greatest extent possible by use of pseudonyms.

In accordance with legal requirements, we will disclose to the appropriate individual's information that comes to our attention concerning child abuse or neglect or potential harm to you or others.

If we write a report or article about this research project, your identity will be protected.

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

There may be some risks from participating in this research study. Some questions may make you feel uncomfortable and embarrassed. All human interactions and talking about others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological

or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

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

This research is not designed to help you personally, but the results may help the investigator learn more about the survival and functioning of persons with traumatic spinal cord injury in South Africa. We hope that, in the future, other people might benefit from this study through improved understanding of survival and functioning of persons with traumatic spinal cord injury in South Africa.

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

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

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

This research is being conducted by Vuyolwethu Madasa, Physiotherapy Department at the University of the Western Cape. If you have any questions about the research study itself, please contact Dr Conran Joseph at: 021-959 3662 or cell 0723719276, email address: [cjoseph@uwc.ac.za](mailto:cjoseph@uwc.ac.za).

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:

Dr Nondwe Mlenzana  
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## Appendix 3: English Information Sheet for Participants



# UNIVERSITY OF THE WESTERN CAPE

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## INFORMATION SHEET FOR PARTICIPANTS

**Project Title: Survival and secondary medical conditions of persons with traumatic spinal cord injury in South Africa**

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

This research project is being conducted by Vuyolwethu Madasa at the University of the Western Cape. This is a study investigating the survival and secondary medical conditions of persons with traumatic spinal cord injury in South Africa. The main aim is to determine death rates as well as health and wellness needs and to propose how the health system could be improved. There are minimal risks associated with your participation in this research project since no intervention will be applied.

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

You will be asked to attend a session, a place convenient to you, with one of the researchers and answer questions related to your injury and functional capabilities. Family members of those who have passed on will be requested to provide a death certificate and information on cause of death.

### **Would my participation in this study be kept confidential?**

Participants will be asked to complete the survey, all information attained will be kept confidential. We will do our best to keep your personal information confidential. To help protect your confidentiality, all information gathered will be stored in a locked filing cabinet. No unauthorised parties will have access to your information. Names of participants will be replaced by a unique study code which will be used throughout the study. In the event of writing a report or article, your identity will be protected to the greatest extent possible by use of pseudonyms.

In accordance with legal requirements, we will disclose to the appropriate individual's information that comes to our attention concerning child abuse or neglect or potential harm to you or others.

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

There are minimal risks associated with participating in this research project. If any harm is caused, we shall make the appropriate referral to an appropriate healthcare provider in the participant's local area. Depending on participants needs, they will be referred to the local clinic, local social workers, psychologist, physiotherapist, occupational therapist or psychologist for emotional trauma counselling.

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

On a personal level, you will gain an understanding on how the injury affected you and how you function in relation to others with similar injuries. On a broader level, this information could assist with the strengthening of health systems for persons with SCI in South Africa.

### **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?**

There are minimal risks associated with your participation in this study. If the participant becomes emotional due to the nature of the questions, we will suggest seeking help from an appropriate health professional in the community.

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

This research is being conducted by Vuyolwethu Madasa, Physiotherapy Department at the University of the Western Cape. If you have any questions about the research study itself, please contact Dr Conran Joseph at: 021-959 3662 or cell 0723719276, email address: [cjoseph@uwc.ac.za](mailto:cjoseph@uwc.ac.za).

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:

Dr Nondwe Mlenzana  
Head of Department: Physiotherapy  
University of the Western Cape  
Private Bag X17  
Bellville 7535  
[nmlenzana@uwc.ac.za](mailto:nmlenzana@uwc.ac.za)

Prof R Swart  
Dean of the Faculty of Community and Health Sciences  
University of the Western Cape  
Private Bag X17  
Bellville 7535  
[chs-deansoffice@uwc.ac.za](mailto:chs-deansoffice@uwc.ac.za)

## Appendix 4: Afrikaans Information Sheet for Carers



# UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 71 614 2879

E-mail: 29272828@myuwc.ac.za

## INLIGTINGSBYLAE VIR VERSORGER

**Titel van Projek:** Oorlewing en sekondêre mediese toestande van persone met traumatiese spinaalkoordbeserings in Suid Afrika

### **Waaroor gaan hierdie studie?**

Hierdie navorsingsprojek word deur Vuyolwethu Madasa by die Universiteit van Weskaapland uitgevoer. Die studie ondersoek die oorlewing en sekondêre mediese toestande van persone met traumatiese spinaalkoordbeserings in Suid Afrika.

### **Wat sal van my verwag word indien ek aan die studie sou deelneem?**

Dit sal van u as sorger verwag word om die oorsaak van dood te bevestig.

### **Sal my identiteit anoniem bly?**

Ons sal ons bes doen om u persoonlike inligting vertroulik te hou. Om dit te verseker sal inligting in 'n geslote plek gestoor word. Geen ongemagtigde persone sal toegang tot die inligting hê nie. In die geval van 'n artikel of 'n verslag, sal u identiteit ten beste van ons vermoë beskerm word. Weens wetlike vereistes en om professionele standarde te behou, sal ons inligting wat kindermishandeling, nalatigheid of potensiële gevaar aandui aan gepaste individue oordra.

### **Wat is die risiko's van hierdie navorsing?**

Daar is minimale risiko's verbonde aan deelname van hierdie navorsingsprojek. Indien die behoefte ontstaan om 'n verwysing van die toestand van die deelnemer te maak wat in die belang van die deelnemer is, sal sodanige verwysing gedoen word.

### **Wat is die voordele van hierdie navorsing?**

Op 'n breër vlak, kan u inligting bydrae tot die versterking van die gesondheidstelsels vir persone met rugmurgbeserings in Suid Afrika.

### **Is ek verplig om deel van hierdie navorsing te wees en mag ek op enige oomblik onttrek?**

U deelname is vrywillig. U het die keuse om nie deel van die studie te wees nie. Sou u besluit om deel te neem, mag u enige oomblik besluit om van die studie te onttrek. Sou u besluit om nie deel te neem nie of tydens die studie op te hou, sal u nie gepenaliseer word of enige voordele verloor waarvoor u tans kwalifiseer nie.

### **Wat gebeur as ek vrae het?**

Hierdie navorsing is deur Vuyolwethu Madasa gedoen, Fisioterapie Department by die Universiteit van die Wes-Kaapland. Sou u enige vrae oor die navorsingstudie hê, kan u Dr Conran Joseph kontak by:0219593662 of sel: 0723719276 epos: [cjoseph@uwc.ac.za](mailto:cjoseph@uwc.ac.za). Enige vrae omtrent die studie en u regte as deelnemer of as u enige klagtes het, kontak:

Dr Nondwe Mlenzana  
Head of Department: Physiotherapy  
University of the Western Cape  
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Bellville 7535  
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## Appendix 5: Afrikaans Information Sheet for Participants



# UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 71 614 2879

E-mail: 29272828@myuwc.ac.za

## INLIGTINGSBYLAE VIR DEELNEMERS

**Titel van Projek:** Oorlewing en sekondêre mediese toestande van persone met traumatiese spinaalkoordbeserings in Suid Afrika

### Waaroor gaan hierdie studie?

Hierdie navorsingsprojek word deur Vuyolwethu Madasa by die Universiteit van Weskaapland uitgevoer. Die studie ondersoek die oorlewing en sekondêre mediese toestande van persone met traumatiese spinaalkoordbeserings in Suid Afrika. Informasie wat gebruik mag word vir die versterking van gesondheidsdienste. Daar is minimale risikos verbonde aan u deelname in die studie omdat geen intervensie toegepas sal word nie.

### Wat sal van my verwag word indien ek aan die studie sou deelneem?

Sou u toestem om aan die studie deel te neem, sal van u verwag word om 'n 45 minute lange vraelys te voltooi in u voorkeur taal, wat u kan kies om telefonies of in persoon te voltooi. Die vrae behels aspekte soos oorlewingsstatus, funksionering en gesondheidstoestand. Indien die deelnemer sou sterf sal daar van die versorger verwag word om die doodsertifikaat beskikbaar te maak en ook die oorsaak van dood te bevestig.

### Sal my identiteit anoniem bly?

Ons sal ons bes doen om u persoonlike inligting vertroulik te hou. Om dit te verseker sal inligting in 'n geslote plek gestoor word. Geen ongemagtigde persone sal toegang tot die inligting hê nie. In die geval van 'n artikel of 'n verslag, sal u identiteit ten beste van ons vermoë beskerm word. Weens wetlike vereistes en om professionele standarde te behou, sal ons inligting wat kindermishandeling, nalatigheid of potensiële gevaar aandui aan gepaste individue oordra.

### Wat is die risiko's van hierdie navorsing?

Daar is minimale risiko's verbonde aan deelname in hierdie navorsingsprojek. Indien die behoefte ontstaan om 'n verwysing van die toestand van die deelnemer te maak wat in die belang van die deelnemer is, sal sodanige verwysing gedoen word.

### Wat is die voordele van hierdie navorsing?

Op 'n persoonlike vlak sal u insig kry in hoe die besering u geaffekteer het en hoe u funksie in vergelyking met ander met soortgelyke beserings vergelyk. Op 'n breër

vlak, kan u inligting bydrae tot die versterking van die gesondheidstelsels vir persone met rugmurgbeserings in Suid Afrika

**Is ek verplig om deel van hierdie navorsing te wees en mag ek op enige oomblik onttrek?**

U deelname is vrywillig. U het die keuse om nie deel van die studie te wees nie. Sou u besluit om deel te neem, mag u enige oomblik besluit om van die studie te onttrek. Sou u besluit om nie deel te neem nie of tydens die studie op te hou, sal u nie gepenaliseer word of enige voordele verloor waarvoor u tans kwalifiseer nie.

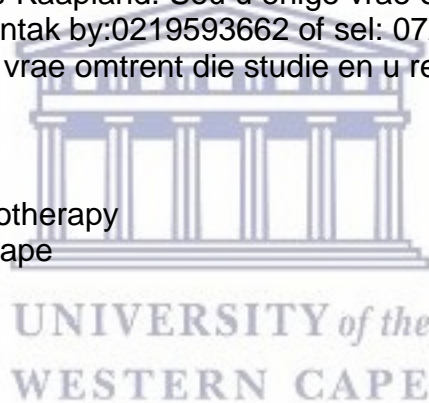
**Is daar hulp beskikbaar as ek op enige manier negatief beïnvloed word deur hierdie studie?**

Daar is geen bekende risiko's verbonde aan deelname aan hierdie studie nie. Maar sou u as deelnemer emosioneel raak as gevolg van die vrae, sal u verwys word na die geskikte gesondheidspraktisyn.

**Wat gebeur as ek vrae het?**

Hierdie navorsing is deur Vuyolwethu Madasa gedoen, Fisioterapie Department by die Universiteit van die Wes-Kaapland. Sou u enige vrae oor die navorsingstudie hê, kan u Dr Conran Joseph kontak by: 0219593662 of sel: 0723719276 epos: [cjoseph@uwc.ac.za](mailto:cjoseph@uwc.ac.za). Enige vrae omtrent die studie en u regte as deelnemer of as u enige klagtes het, kontak:

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Head of Department: Physiotherapy  
University of the Western Cape  
Private Bag X17  
Bellville 7535  
[nmlenzana@uwc.ac.za](mailto:nmlenzana@uwc.ac.za)



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Dean of the Faculty of Community and Health Sciences  
University of the Western Cape  
Private Bag X17  
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## Appendix 6: IsiXhosa Information Sheet for Carers



# UNIVERSITY OF THE WESTERN CAPE

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Tel: +27 71 614 2879

E-mail: 29272828@myuwc.ac.za

### **IPHEPHA LENCAZELO KWABO BATHATHA INXAXHEBA**

**Isihloko sophando:** Ukuphila nobumi bempilo yabantu abahlaselwe kukonzakala komnqonqo eMzantsi Afrika

#### **Lungantoni olu phando?**

Olu phando lwenziwa nguVuyolwethu Madasa kwiDyunivesithi yeNtshona Koloni. Olu phando lukhangela ukuphila nobume bempilo kubantu abathe bahlaselwa kukonzakala komnqonqo eMzantsi Afrika. Eyona njongo yoluphando kukujonga ukufa, impilo, izidingo zempilo kunye nokujonga ukuba inkqubo yezempilo ingaphuculwa njani. Kuba wena ungomnye wosapho/lowo obenakekela lowo obethe wonzakala umnqonqo sicela wena usiphendulele imibuzo. Ngokweza olu phando sizama ukuqinisa ubumi bezempilo eMzantsi Afrika.

#### **Kuzakubuzwa ntoni ukuba ndiyavuma ukuthatha inxaxheba**

Uzakucelwa ukuba udibane nomphandi endaweni elula kuwe, uphendule imibuzo ejongene nesigulo salowo ubuhlala naye nonobangela wokuba ade asweleke. Uzakucelwa unikezele ngesiqinisekiso sokufa.

#### **Ingaba ukuthatha kwam inxaxheba kuzokugcinakala kuyimfihlo?**

Sizokwenza konke okusemandleni ethu ukugcina inkcukacha zakho ziyimfihlo. Ukunceda ukukhusela inkcukacha zakho, zonke izinto zophando zizokufakwa kwikhabhinethi etsixwayo. Akukho mntu ongenamvume ozokufikelela kwinkcukacha zakho. Apho kufuneka sibhale icwecwe ngophando olu, inkcukacha zokuba ungubaniwaphi zizokufihlakala.

Ngokwezomthetho, zizakuzichaza inkcukacha zabo barhaneleka ngokuhlukumeza umntwana, ukungamhoyi umntwana nabo bangakonzakalisa.

#### **Ziziphi iingozi yolu phando?**

Akukho Ubungozi obaziwayo enxulumene inxaxheba kule projekthi yophando Ukuba nawuphi na umonakalo siya kwenza yokudlulisela efanelekileyo.

#### **Ikhona na inzuzo kolu phando?**

Mntu ngamnye, uya kuzuza ukuqonda indlela ukwenzakala ochaphazelekayo wena nendlela

umsebenzi ngokunxulumene kwabanye elimele efanayo. Ngokwembono ngokubanzi, le nkcazelo ukunceda kunye nokomelezwa iinkqubo zempilo kubantu Sci eMzantsi Afrika.

### **Ingaba ndinyanzelekile na ukuba ndithathe inxaxheba kolu phando kwaye ndiyeke nangeliph ixesha ndifuna?**

Inxaxheba kwakho kolu phando kukuzithandela ngokupheleleyo. Ungakhetha ukuthatha inxaxheba okanye ungavumi kwaphela. Ukuba ugqiba ekubeni uthathe inxaxheba ze ungafuni, unalo ilungelo lokuyeka. Ukuba ugqiba ukuba ungathathi inxaxheba kolu phando okanye ukuba uyeke, awusayi kohlwaywa okanye ulahlekelwe naziphi na izibonelelo obekumele ukuba uyazifumana.

### **Ingaba lukhona na uncedo olufumanekayo xa ndithe ndachaphazeleka kakubi mna ngokuthatha inxaxheba kwesi sifundo?**

Akukho bungozi obunxulumene ne nxaxheba yakho kolu phando. Kodwa ke, ukuba lowo uthatha inxaxheba uba neemvakalelo ngenxa yobume le mibuzo, siya siphakamisa sifuna uncedo evela umsebenzi wezempilo efanelekileyo ekuhlaleni.

### **Ukuba ndinemibuzo**

Olu phando lwenziwa nguVuyolwethu Madasa, ePhysiotherapy, kwiDyunivesithi yeNtshona Koloni.

Ukuba unemibuzo ngoluphando, gqagamshela uDr Conran Joseph kwinombolo: 021-959 3662 okanye 0723719276, idilesi ye-email: [cjoseph@uwc.ac.za](mailto:cjoseph@uwc.ac.za).

Ukuba unemibuzo malunga noluphando kunye namalungelo akho njengalowo othatha inxaxheba koluphando okanye ufuna ukukhalaza ngengxaki othe wabanazo ngoluphando nceda qhagamshela aba balandelayo:

Dr Nondwe Mlenzana  
Head of Department: Physiotherapy  
University of the Western Cape  
Private Bag X17  
Bellville 7535  
[nmlenzana@uwc.ac.za](mailto:nmlenzana@uwc.ac.za)

Prof R Swart  
Dean of the Faculty of Community and Health Sciences  
University of the Western Cape  
Private Bag X17  
Bellville 7535  
[chs-deansoffice@uwc.ac.za](mailto:chs-deansoffice@uwc.ac.za)



## Appendix 7: IsiXhosa Information Sheet for Participants



# UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 71 614 2879

E-mail: 29272828@myuwc.ac.za

### IPHEPHA LENCAZELO KWABO BATHATHA INXAXHEBA

**Isihloko sophando:** Ukuphila nobumi bempilo yabantu abahlaselwe kukonzakala komnqonqo eMzantsi Afrika

#### **Lungantoni olu phando?**

Olu phando lwenziwa nguVuyolwethu Madasa kwiDyunivesithi yeNtshona Koloni. Olu phando lukhangela ukuphila nobume bempilo kubantu abathe bahlaselwa kukonzakala komnqonqo eMzantsi Afrika. Eyona njongo yoluphando kukujonga ukufa, impilo, izidingo zempilo kunye nokujonga ukuba inkqubo yezempilo ingaphuculwa njani.

#### **Kuzakubuzwa ntoni ukuba ndiyavuma ukuthatha inxaxheba**

Uzakucelwa ukuba udibane nomphandi endaweni elula kuwe, uphendule imibuzo ejongene nesigulo sakho nezinto okwaziyo ukuzenzela. Izihlobo nezalamane zabo ebesele besandulele zizakucelwa zinikezele ngesiqinisekiso sokufa kunye nembangela yokufa.

#### **Ingaba ukuthatha kwam inxaxheba kuzokugcinakala kuyimfihlo?**

Sizokwenza konke okusemandleni ethu ukugcina ikcukacha zakho ziyimfihlo. Ukunceda ukukhusela inkukacha zakho, zonke izinto zophando zizokufakwa kwikhabhinethi etsixwayo. Akukho mntu ongenamvume ozokufikelela kwinkcukacha zakho. Apho kufuneka sibhale icwecwe ngophando olu, inkukacha zokuba ungubaniwaphi zizokufihlakala.

Ngokwezomthetho, zizakuzichaza inkcukacha zabo barhaneleka ngokuhlukumeza umntwana, ukungamhoyi umntwana nabo bangakonzakalisa.

#### **Ziziphi iingozi yolu phando?**

Akukho Ubungozi obaziwayo enxulumene inxaxheba kule projekthi yophando Ukuba nawuphi na umonakalo siya kwenza yokudlulisela efanelekileyo.

#### **Ikhona na inzuzo kolu phando?**

Mntu ngamnye, uya kuzuza ukuqonda indlela ukwenzakala ochaphazelekayo wena nendlela umsebenzi ngokunxulumene kwabanye elimele efanayo. Ngokwembono ngokubanzi, le nkcazelo ukunceda kunye nokomelezwa iinkqubo zempilo kubantu Sci eMzantsi Afrika.

## **Ingaba ndinyanzelekile na ukuba ndithathe inxaxheba kolu phando kwaye ndiyeke nangeli ixesha ndifuna?**

Inxaxheba kwakho kolu phando kukuzithandela ngokupheleleyo. Ungakhetha ukuthatha inxaxheba okanye ungavumi kwaphela. Ukuba ugqiba ekubeni uthathe inxaxheba ze ungafuni, unalo ilungelo lokuyeka. Ukuba ugqiba ukuba ungathathi inxaxheba kolu phando okanye ukuba uyeke, awusayi kohlwaywa okanye ulahlekelwe naziphi na izibonelelo obekumele ukuba uyazifumana.

## **Ingaba lukhona na uncedo olufumanekayo xa ndithe ndachaphazeleka kakubi mna ngokuthatha inxaxheba kwesi sifundo?**

Akukho bungozi obunxulumene ne nxaxheba yakho kolu phando. Kodwa ke, ukuba lowo uthatha inxaxheba uba neemvakalelo ngenxa yobume le mibuzo, siya siphakamisa sifuna uncedo evela umsebenzi wezempilo efanelekileyo ekuhlaleni.

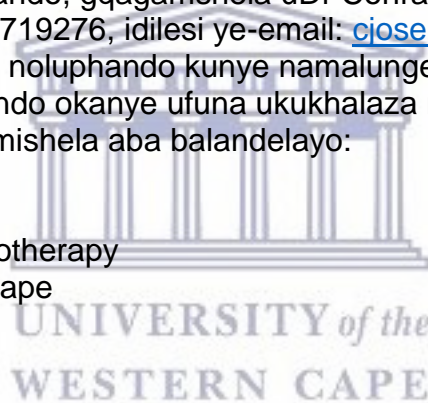
## **Ukuba ndinemibuzo**

Olu phando lwenziwa nguVuyolwethu Madasa, ePhysiotherapy, kwiDyunivesithi yeNtshona Koloni.

Ukuba unemibuzo ngoluphando, gqagamshela uDr Conran Joseph kwinombolo: 021-959 3662 okanye 0723719276, idilesi ye-email: [cjoseph@uwc.ac.za](mailto:cjoseph@uwc.ac.za).

Ukuba unemibuzo malunga noluphando kunye namalungelo akho njengalowo othatha inxaxheba koluphando okanye ufuna ukukhalaza ngengxaki othe wabanazo ngoluphando nceda qhagamishela aba balandelayo:

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## Appendix 8: English InSCI Questionnaire



# International Spinal Cord Injury Survey (InSCI)



UNIVERSITY of the  
*The first worldwide survey*  
WESTERN CAPE

*on community-dwelling persons with spinal cord injury.*

*Countries all over the world take part in this initiative to capture the experience of living with spinal cord injury by asking those who know best: persons with spinal cord injury.*

*A collaboration of*





Dear participant

***Welcome to the InSCI survey, we are very happy to have you on board!***

InSCI is the first worldwide survey on community-dwelling persons with spinal cord injury. Countries all over the world take part in this initiative to capture the experience of living with spinal cord injury by asking those who know best: persons with spinal cord injury.

Please fill in the questionnaire as completely as possible and don't leave any questions unanswered. There is no right or wrong and no good or bad answer. It is important that you answer spontaneously and decide which response best applies to your personal situation.

You can also complete the questionnaire online at [www.insci.com](http://www.insci.com). Please login with your InSCI-ID and your personal password:

Your InSCI-ID is: #####

Your personal password is: #####



We guarantee that your data is protected with the highest security standards. No personal data will be handed out to third persons outside the study center. All questionnaires are anonymized by a unique identification number (InSCI-ID) and there is no personal information such as name or address on the paper or online questionnaire.

In case you have any question or need support in questionnaire completion, we are happy to help. Please send us an email at [contact@en.insci.network](mailto:contact@en.insci.network) or contact our toll-free InSCI-helpline at 0700 523 696 631.

Thank you again for your commitment!

*Your RSA InSCI-Team*

Dr Conran Joseph

## Personal information

---

1. Please indicate your gender:

- Male
- Female

2. What day, month and year were you born?

DD / MM / YYYY

/   /

3. In which country were you born?





 .....

4. What is your current marital status?

- Single
- Married
- Cohabiting or in a partnership
- Separated or divorced
- Widowed

5. Who lives in your household with you?

*Check all that apply*

- I live alone
- Children under 14 years of age, number:  .....
- Youth between 14 and 18 years of age, number:  .....
- Persons between 18 and 64 years of age, number:  .....
- Persons over 64 years of age, number:  .....
- I live in an institution e.g. *home for the elderly, nursing home*

6. Do you get assistance with your day-to-day activities at home or outside?


- No
- Yes, by the following persons:

*Check all that apply*


- Family
- Friends
- Professionals or paid assistants


7. What is the highest level of education that you have completed?

- Primary
- Lower secondary
- Higher secondary
- Post-secondary
- Short tertiary
- Bachelor or equivalent

- Master or equivalent
- Other, namely:  .....

**8. How many years of education or training have you completed?**

Years of education or training before your spinal cord injury:  ..... (Number of years)

Years of education or training after your spinal cord injury:  ..... (Number of years)

**9. Taking into account all persons living in your household who work for a salary or wage: what is the total household income taxes on average per month?**

- Less than R1100 per month
- R1101 – R3000 per month
- R3001 –R4500 per month
- R4501 – R6000 per month
- R6001 –R9000 per month
- R9001 – R12000 per month
- R12001 – R20 000 per month
- R20001 – R3000 per month
- R30001 – R50000 per month
- R500001 or more

**10. Think of this ladder as representing where people stand in *South Africa*.**

At the top of the ladder are the people who are the best off - those who have the most money, the most education and the most respected jobs. At the bottom are the people who are the worst off – who have the least money, least education, and the least respected jobs or no job. The higher up you are on this ladder, the closer you are to the people at the very top; the lower you are, the closer you are to the people at the very bottom.

**Where would you place yourself on this ladder?**

Please place a large **X** on the rung where you would place yourself at this time in your life, relative to other people in *South Africa*



## Lesion characteristics

---

**11. Please describe the level of your spinal cord injury:**

- Paraplegia (normal movement and feeling in the upper limbs)
- Tetraplegia (absent or abnormal movement or feeling in the upper and lower limbs)

**12. Is your injury complete or incomplete?**

- Complete (unable to feel and move any part of your body below injury level)
- Incomplete (able to feel or move some part/s of your body below injury level)

**13. Please indicate the cause of your spinal cord injury:**

*Caused by injury:*

*Check all that apply*

*For example if you check the box 'accident during work', please also specify if it was a fall or another cause of injury.*

- Accident during sports
- Accident during leisure activity
- Accident during work
- Traffic accident
- Injury due to violence *e.g., gunshot wound*
- Fall from less than 1 meter
- Fall from more than 1 meter
- Other cause of injury: *✎* .....

*Caused by disease:*

*Check all that apply*

- Degeneration of the spinal column
- Tumor – benign
- Tumor – malignant (cancer)
- Vascular problem *e.g., ischemia, hemorrhage, malformations*
- Infection *e.g., bacterial, viral*
- Other disease: *✎* .....

**14. Please indicate as precisely as possible the date on which your spinal cord injury occurred:**

DD / MM / YYYY

□□/□□/□□□□

## Energy and feelings

These questions are about how you have felt and how things have been with you during the last 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the <u>last 4 weeks</u> ...	<i>All of the time</i>	<i>Most of the time</i>	<i>Some of the time</i>	<i>A little of the time</i>	<i>None of the time</i>
15. Did you feel full of life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Have you been very nervous?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Have you felt so down in the dumps that nothing could cheer you up?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Have you felt calm and peaceful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Did you have a lot of energy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Have you felt downhearted and depressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Did you feel worn out?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Have you been happy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Did you feel tired?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



## Health problems

For the following health problems please rate how much of a problem it was for you in the last 3 months. If you have experienced the health problem please indicate whether you have received treatment or not (e.g., taking a medication or getting treatment by doctors or other health professionals).

	1 No problem	2	3	4	5 Extreme problem	Do/did you receive treatment for it?
<b>24. Sleep problems</b> <i>e.g., problems falling asleep or sleeping through the night and waking up early.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
<b>25. Bowel dysfunction</b> <i>e.g., diarrhea, stool incontinence ('accidents') and constipation.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
<b>26. Urinary tract infections</b> <i>e.g., kidney or bladder infection.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
<b>27. Bladder dysfunction</b> <i>e.g., incontinence ('accidents'), bladder or kidney stones, kidney problems, urine leakage and urine back up.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
<b>28. Sexual dysfunction</b> <i>e.g., difficulty with sexual arousal, erection, lubrication, and reaching orgasm.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
<b>29. Contractures</b> <i>This is a limitation in the range of motion of a joint.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
<b>30. Muscle spasms, spasticity</b> <i>This refers to uncontrolled, jerky muscle movements, such as uncontrolled muscle twitches or spasms.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
<b>31. Pressure sores, decubitus</b> <i>These develop as a skin rash or redness and may progress to an infected sore.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No

<p><b>32. Respiratory problems</b> Symptoms of respiratory infections or problems include difficulty in breathing and increased secretions.</p>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
<p><b>33. Injury caused by loss of sensation</b> e.g., burns from carrying hot liquids in the lap or sitting too close to a heater or fire.</p>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
<p><b>34. Circulatory problems</b> This involves the swelling of veins, feet, legs or hands, or the occurrence of blood clots.</p>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>  1 No problem      2      3      4      5 Extreme problem	<input type="radio"/> Yes <input type="radio"/> No  Do/did you receive treatment for it?
<p><b>35. Autonomic dysreflexia</b> Symptoms are sudden rises in blood pressure and sweating, skin blotches, goose bumps, pupil dilation and headache.</p>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
<p><b>36. Postural hypotension</b> This involves a strong sensation of lightheadedness following a change in position. It is caused by a sudden drop in blood pressure.</p>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
<p><b>37. Pain</b> Having pain in your day-to-day life.</p>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No

**38. Please rate your pain by circling the number that best describes your pain at its worst in the last week.**



**39. Please name up to five additional health problems that also bother you:**

- No additional health problem experienced

 .....

 .....

 .....

 .....

 .....

**40. Please indicate your current smoking status:**

- Never smoked
- Former smoker
- Current smoker (including occasional smoker)



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## Activity and participation

The following section is about problems you experience in your life. Please take both good and bad days into account.

In the <u>last 4 weeks</u> , how much of a problem have you had...	1 <i>No problem</i>	2	3	4	5 <i>Extreme problem</i>
41. ... carrying out daily routine?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
42. ... handling stress?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
43. ... doing things that require the use of your hands and fingers, such as picking up small objects or opening a container?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
44. ... getting where you want to go?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
45. ... using public transportation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46. ... using private transportation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
47. ... looking after your health, eating well, exercising or taking your medicine?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
48. ... getting your household tasks done?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
49. ... providing care or support for others?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
50. ... interacting with people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
51. ... with intimate relationships?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
52. ... doing things for relaxation or pleasure?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
53. ... with shortness of breath during physical exertion?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
54. Are you able to sit unsupported? <input type="radio"/> No <input type="radio"/> Yes → How much of a problem is sitting for long periods such as 30 minutes?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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55. Are you able to stand unsupported?

- No
- Yes → How much of a problem is standing for long periods such as 30 minutes?



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These questions ask about your ability to do activities that involve mobility. Select the response that best describes your ability to do the activity without help from another person but using the equipment or devices you normally use (e.g., transfer boards lifts, hospital bed).

Are you able to...	<i>Without any difficulty</i>	<i>With a little difficulty</i>	<i>With some difficulty</i>	<i>With much difficulty</i>	<i>Unable to do</i>
56. ...get up off the floor from lying on your back?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
57. ...push open a heavy door?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
58. ...moving from sitting at the side of the bed to lying down on your back?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



## Independence in activities of daily living

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For each item, please check the box next to the statement that best reflects your current situation. Please read the text carefully and only check one box in each section.

### 59. Eating and drinking

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

### 60. Washing your upper body and head

*This includes soaping and drying, and using a water tap.*

- I need total assistance
- I need partial assistance
- I am independent but need adaptive devices or specific equipment *e.g., bars, chair*
- I am independent and do not need adaptive devices or specific equipment

### 61. Washing your lower body

*This includes soaping and drying, and using a water tap.*

- I need total assistance
- I need partial assistance
- I am independent but need adaptive devices or specific equipment *e.g., bars, chair*
- I am independent and do not need adaptive devices or specific equipment

### 62. Dressing your upper body

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

- *Easy-to-dress clothes are those without buttons, zippers or laces*
- *Difficult-to-dress clothes are those with buttons, zippers or laces*
- I need total assistance
- I need partial assistance, even with easy-to-dress clothes
- I do not need assistance with easy-to-dress clothes, but I need adaptive devices or specific equipment
- I am independent with easy-to-dress clothes and only need assistance or adaptive devices or a specific setting with difficult-to-dress clothes
- I am completely independent

### 63. Dressing your lower body

*This includes putting on and taking off clothes like shorts, trousers, shoes, socks, belts, or orthoses (e.g., leg splint).*

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

- *Difficult-to-dress clothes are those with buttons, zippers or laces*
- I need total assistance
- I need partial assistance, even with easy-to-dress clothes
- I do not need assistance with easy-to-dress clothes, but I need adaptive devices or specific equipment
- I am independent with easy-to-dress clothes and only need assistance or adaptive devices or a specific setting with difficult-to-dress clothes
- I am completely independent

**64. Grooming**

*e.g., activities such as washing hands and face, brushing teeth, combing hair, shaving, or applying make-up.*

- I need total assistance
- I need partial assistance
- I am independent with adaptive devices
- I am independent without adaptive devices

**65. Bladder management**

*Please think about the way you empty your bladder.*

**A. Use of an indwelling catheter**

- Yes → *Please go to question no. 66*
- No → *Please also answer B and C.*

**B. Intermittent catheterization**

- I need total assistance
- I do it myself with assistance (self-catheterization)
- I do it myself without assistance (self-catheterization)
- I do not use it

**C. Use of external drainage instruments** *e.g., condom catheter, diapers, sanitary napkins*

- I need total assistance for using them
- I need partial assistance for using them
- I use them without assistance
- I am continent with urine and do not use external drainage instruments

**66. Bowel management**

**A. Do you need assistance with bowel management** *e.g., for applying suppositories?*

- Yes
- No

**B. My bowel movements are...**

- irregular or seldom (less than once in 3 days)
- regular (once in 3 days or more)

**C. Fecal incontinence (“accidents”) happens ...**

- Daily
- 1-6 times per week
- 1-4 times every month
- Less than once per month
- Never



**67. Using the toilet**

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

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

**68. Which of the following activities can you perform without assistance or electrical aids?**

*Check all that apply*

- Turning your upper body in bed
- Turning your lower body in bed
- Sitting up in bed
- Doing push-ups in a chair or wheelchair
- None, I need assistance in all these activities

**69. Transfers from the bed to the wheelchair**

- I need total assistance
- I need partial assistance, supervision or adaptive devices e.g., sliding board
- I do not need any assistance or adaptive devices
- I do not use a wheelchair

**70. Moving around moderate distances (10 to 100 meters)**

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

- I need total assistance
- I need an electric wheelchair or partial assistance to operate a manual wheelchair
- I am independent in a manual wheelchair

I walk moderate distances and I ...

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

71. What was the name or title of your main job before your spinal cord injury?

- I did not have a job before my spinal cord injury.

The name or title of my main job was as follows (*please be as specific as possible, e.g., not just 'clerk' but 'bank clerk'; not just 'manager' but 'sales manager'*)

.....

72. Did you receive vocational rehabilitation services after your spinal cord injury?

*e.g., vocational counseling, vocational retraining, job skills training*

- Yes
- No

73. After your discharge from initial inpatient rehabilitation, how long did it take before you started or resumed paid work?

- I never worked after initial inpatient rehabilitation
- Immediately after initial rehabilitation
- I resumed work after ..... years and ..... months

74. Do you currently receive a disability pension or a similar disability benefit?

- Yes
- No

75. What is your current working situation?

*Check all that apply*

- Working for wages or salary with an employer for ..... hours a week
- Working for wages with an employer for ..... hours a week, but currently on sick leave for more than three months
- Self-employed, working for ..... hours a week
- Working as unpaid family member *e.g., working in family business*
- Housewife / househusband
- Student
- Unemployed
- Retired due to the health condition
- Retired due to age
- Other, please specify: .....

76. Are you currently engaged in paid work?

- Yes
- No → *Please go to question no. 84*

77. What is the name or title of your current main job?

*Please be as specific as possible, e.g., not just 'clerk' but 'bank clerk'; not just 'manager' but 'sales manager'*

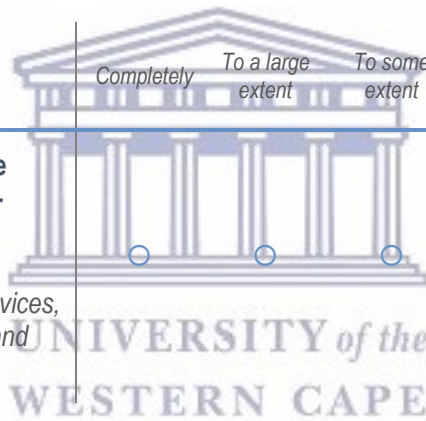
.....

78. Do you want to work more, less or the same amount of hours as you currently do?

- More hours
- Less hours
- The same amount

	1 <i>No problem</i>	2	3	4	5 <i>Extreme problem</i>
79. <b>How much of a problem is getting things done as required at work?</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
80. <b>How much of a problem do you have in accessing your workplace?</b>  <i>e.g., access to the building, your office or toilets</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	<i>Completely</i>	<i>To a large extent</i>	<i>To some extent</i>	<i>To a small extent</i>	<i>Not at all</i>	<i>I do not have such a need</i>
81. <b>Do you have the assistive devices that you need for work?</b>  <i>e.g., assistive computer devices, adjustable desks or arm/hand braces or prosthetics</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



The following two questions refer to your present occupation. For each of the following statements, please indicate whether you strongly agree, agree, disagree or strongly disagree.

	<i>Strongly agree</i>	<i>Agree</i>	<i>Disagree</i>	<i>Strongly disagree</i>
82. <b>I receive the recognition I deserve for my work.</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
83. <b>Considering all my efforts and achievements, my salary is adequate.</b>  <b>→ Please go to question no. 87</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

84. **Would you like to have paid work?**

- Yes
- No

85. **Do you feel able to perform paid work?**

- Yes, for 1 – 11 hours a week
- Yes, for 12 – 20 hours a week
- Yes, for more than 20 hours a week
- No, not at all

86. **What are the reasons you are not currently working?**

*Check all that apply*

- Health condition or disability
- Still engaged in educational or vocational training
- Personal family responsibilities
- Could not find suitable work
- Do not know how or where to seek work
- Do not have the financial need
- Parents or spouse did not let me work
- Insufficient transportation services
- Lack of accessibility to potential workplaces *e.g., access to the building, your office or toilets*
- Lack of assistive devices
- Fear of losing disability benefits *e.g., pension payments, health insurance coverage*
- I do not want to work
- Other, please specify: *✍* .....

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## Environmental factors

In daily life, we are exposed to various external influences or environmental factors. These can make daily life easier or more difficult. Thinking about the last 4 weeks, please rate how much these environmental factors have influenced your participation in society.

	Not applicable	No influence	Made my life a little harder	Made my life a lot harder
87. <b>Missing or insufficient accessibility of public places</b> <i>e.g., inaccessible public buildings, parks</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
88. <b>Missing or insufficient accessibility to the homes of friends and relatives</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
89. <b>Unfavorable climatic conditions</b> <i>e.g., weather, season, temperature, humidity</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
90. <b>Negative societal attitudes toward persons with disability</b> <i>e.g., prejudice, stigma, ignorance</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
91. <b>Negative attitudes of your family and relatives with regards to your disability</b> <i>e.g., prejudice, lack of support, overprotective behavior</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
92. <b>Negative attitudes of your friends with regards to your disability</b> <i>e.g., prejudice, lack of support, overprotective behavior</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
93. <b>Negative attitudes of neighbors, acquaintances and work colleagues with regards to your disability</b> <i>e.g., prejudice, lack of support, overprotective behavior</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
94. <b>Lack of or insufficient adapted assistive technology for moving around over short distances</b> <i>e.g., stair lift, walking aids or wheelchair</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
95. <b>Lack of or inadequate adapted means of transportation for long distances</b> <i>e.g., lack of adapted car or hard to use public transportation</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
96. <b>Lack of or insufficient nursing care and support services</b> <i>e.g., home health care or personal assistance</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

<b>97. Lack of or insufficient medication and medical aids and supplies</b> <i>e.g., catheters, disinfectants, splints, pillows</i>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
<b>98. Problematic financial situation</b> <i>e.g., shortage of money</i>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
<b>99. Lack of or insufficient communication devices</b> <i>e.g., lack of or insufficient writing devices, computer, telephone, mouse</i>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>
<b>100. Lack of or insufficient state services</b> <i>e.g., disability insurance or other benefits</i>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>



## Health care services

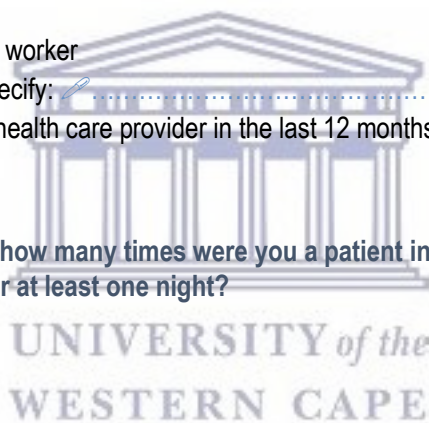
101. Who were the health care providers you visited, or who visited you in your home, in the last 12 months?

*Check all that apply*

- Primary care physician / general practitioner
- Rehabilitation physician / spinal cord injury physician
- Other specialist physician *e.g., surgeon, gynecologist, psychiatrist, ophthalmologist*
- Nurse or midwife
- Dentist
- Physiotherapist
- Chiropractor
- Occupational therapist
- Psychologist
- Alternative medicine practitioner *e.g., naturopath, acupuncturist*
- Pharmacist
- Home health care worker
- Others, please specify: .....
- I did not visit any health care provider in the last 12 months

102. Over the last 12 months, how many times were you a patient in a hospital, rehabilitation facility or another care facility for at least one night?

..... (times)




For your last visit to a health care provider, how would you rate the following:		Very good	Good	Neither good nor bad	Bad	Very bad
103	...your experience of being treated respectfully?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
104	...how clearly health care providers explained things to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
105	...your experience of being involved in making decisions for your treatment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

106 In the last 12 months, have you needed health care but did not get it?

- No
- Yes. Which reasons best explain why you did not get the health care you needed?

Check all that apply

- Could not afford the cost of the visit
- There was no service
- No transport available
- Could not afford the cost of transportation
- You were previously badly treated
- Could not take time off work or had other commitments
- The health care provider's drugs or equipment were inadequate
- The health care provider's skills were inadequate
- You did not know where to go
- You tried but were denied health care
- You thought you were not sick enough
- Other, please specify:  .....

	<i>Very satisfied</i>	<i>Satisfied</i>	<i>Neither satisfied nor dissatisfied</i>	<i>Dissatisfied</i>	<i>Very dissatisfied</i>
<b>107</b> In general, how satisfied are you with how the health care services are run in your area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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## Personal factors

The following questions are about how you see yourself.

	1 <i>Not at all</i>	2	3	4	5 <i>Completely</i>
108 . How confident are you that you can find the means and ways to get what you want if someone opposes you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
109 . How confident are you that you could deal efficiently with unexpected events?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
110 . How confident are you that you can maintain contact with people who are important to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
111 . How confident are you that you can maintain good health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
112 . Do you think that living with your spinal cord injury has made you a stronger person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
113 . Do you worry about what might happen to you in the future? <i>e.g., thinking about not being able to look after yourself, or being a burden to others in the future</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
114 . Do you feel that you will be able to achieve your dreams, hopes, and wishes?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
115 . Do you get to make the big decisions in your life? <i>e.g., deciding where to live, or who to live with, how to spend your money</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
116 . Do you feel included when you are with other people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**117 In the last 12 months, have you experienced any major adverse life event?**

• e.g., a serious health condition or accident, a serious conflict with other persons, divorce or death of a loved one.

- No
- Yes, please specify:  .....

**Quality of life and general health**

---

The next questions are about how you rate your quality of life over the last 14 days. Please keep in mind your standards, hopes, pleasures and concerns.

In the <u>last 14 days</u> ...	Very poor	Poor	Neither poor nor good	Good	Very good
<b>118. How would you rate your quality of life?</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
<b>119. How satisfied are you with your health?</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>120. How satisfied are you with your ability to perform your daily living activities?</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>121. How satisfied are you with yourself?</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>122. How satisfied are you with your personal relationships?</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>123. How satisfied are you with your living conditions?</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**124. In general, would you say your health is:**

- Excellent
- Very good
- Good
- Fair
- Poor

**125. Compared to one year ago, how would you rate your health in general now?**

- Much better
- Somewhat better
- About the same
- Somewhat worse

- Much worse



## Appendix 9: Afrikaans InSCI Questionnaire



# International Spinal Cord Injury Survey (InSCI)



Afrikaanse weergawe

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*Die eerste wereldwye opname van persone met spinale koord beserings wat in die gemeenskap woon.*

*Lande regoor die wereld neem deel aan hierdie initiatief wat behels die evaluasie van die geleefde ervaring om met 'n spinale koord besering te lewe deur diegene te vra wie die beste weet: persone met spinale koord beserings*

*In samewerking met*



Beste Deelnemer

**Welkom by die InSCI opname, ons is baie gelukkig om u aan boord te hê!**

InSCI is die eerste wêreldwye opname oor gemeenskapsgebaseerde woning van persone met rugmurg beserings. Lande regoor die wêreld neem deel aan hierdie initiatief om vas te stel hoe dit is om saam met 'n spinale koord besering te lewe deur die te vra wat die beste kennis het: persone met spinale koord beserings.

Kan u asseblief die vraelys in vul so deeglik as moontlik en moet nie vrae ontgeantwoord laat nie. Daar is geen regte of verkeerde en geen goeie of slegte antwoord nie. Dit is belangrik dat u die spontaan antwoord en self besluit watter opsie die best van toepassing is tot u persoonlike situasie.

U kan ook die vraelys elektronies beantwoord by [[www.insci.com](http://www.insci.com)]. Meld asseblief aan met u InSCI-ID en persoonlike wagwoord:

U InSCI-ID is: #####

U se persoonlike wagwoord is: #####

Ons waarborg dat u data beskerm is met die hoogste sekuriteit standaard. Geen persoonlike data sal oorgehandel word aan 'n derde persoon wat nie deel van die studie sentrum is nie. All vraelyste is anoniem en word by 'n unieke nommer (InSCI-ID) herken, en daar is geen persoonlike informasie soos name of adres op die papier of elektroniese vraelys nie.

In die geval u enige vrae of hulp nodig het met die vraelys, skakel ons gerus. Stuur ons asseblief 'n e-pos aan [contact@rsi.insci.network](mailto:contact@rsi.insci.network) of skakel ons tolvry InSCI-helplyn by 021 959 2542.

Weereens dankie vir u verbintenis!



## Persoonlike Inligting

---

1. Dui asseblief u geslag aan:

- Manlik
- Vroulik

2. Op watter dag, maand en jaargetal was u gebore?

DD / MM / JJJJ

/   /

3. In watter land was u gebore?

.....

4. Wat is u huidige huwelikstaat?

- Enkelopend
- Getroud
- Saamwoonverhouding of in vennootskap
- Uiteengegaan of geskei
- Weduwee of wewenaar

5. Wie maak nog deel uit van u huishouding?

*Merk als wat van toepassing is*

- Ek woon alleen
- Kinders onder 14 jaar, aantal: .....
- Jeug tussen 14 en 18 jaar oud, aantal: .....
- Persone tussen 18 en 64 jaar oud, aantal: .....
- Persone ouer as 64 jaar oud, aantal: .....
- Ek woon in 'n instelling b.v. ouetehuis, verpleeginrigting.....

6. Kry u bystand vir u dag-tot-dag aktiwiteite by die huis of buite?

- Nee
- Ja, by die volgende persone:  
*Merk als wat van toepassing is*
  - Familie
  - Vriende
  - Professionele of betaalde helpers

7. Wat is die hoogste vlak van opvoeding wat u voltooi het?

- Primêre
- Laer sekondêre

- Hoër sekondêre
- Verkorte tersiêre
- Baccalaureus Graad of ekwivalent
- Meesters of ekwivalent
- Ander, naamlik: □ .....

**8. Heoveel jare van studie het u voltooi?**

Jare van opvoeding en opleiding voor die spinale koord besering: □..... (aantal jare)

Jare van opvoeding en opleiding na die spinale koord besering: □..... (aantal jare)

**9. As u in ag sou neem al die werkende persone in u huishouding wat 'n salaries of loon verdien, wat is die totale inkomste [na belasting] van u huishouding per maand?**

- Minder as R1100 per maand
- R1101 – R3000 per maand
- R3001 –R4500 per maand
- R4501 – R6000 per maand
- R6001 –R9000 per maand
- R9001 – R12000 per maand
- R12001 – R20 000 per maand
- R20001 – R3000 per maand
- R30001 – R50000 per maand
- R500001 of meer

**10. Dink aan hierdie leer as verteenwoordigend aan waar mense staan in Suid-Afrika.**

Aan die bo-punt van die leer is die mense wat die beste daaraan toe is – diegene wat die meeste geld besit, die hoogste geleerdheid asook die mees gerespekteerde beroepe. Aan die onderste punt van die leer is diegene wat die minste geld het, die minste geleerdheid asook die minste gerespekteerde beroepe en ook geen werk nie. Hoe hoer op die leer u uself bevind, hoe nader is u aan die persone aan die toppunt, en hoe laer op die leer u uself bevind, hoe nader is u aan die persone op die laagste punt.

**Waar sal u uself op hierdie leer plaas?**

Plaas asseblief 'n groot X op die rang waar u dink u staan op hierdie tydstip van u lewe, in verhouding tot ander mense in Suid-Afrika.

adder?  
k you stand  
United States.



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11. **Beskryf asseblief die vlak van u spinale koord besering.**

- Parapleeg (normale krag in arms, hande en vingers)
- Tetrapleeg (Geen of abnormale beweging or gevoel in arms en bene)

12. **Is u besering volledig (complete) of onvolledig (incomplete)?**

- Volledig (geen gevoel in enige deel van die liggaam onder die beseringsvlak).
- Onvolledig (het gevoel en kan 'n deel of dele van die liggaam beweeg onder beseringsvlak).

13. **Dui asseblief die oorsaak van u spinale koord besering aan:**

*Oorsaak deur besering:*

*Merk als wat van toepassing is*

*Bv. As u ongeluk gedurende werk merk, moet u ook aandei of dit 'n val of ander oorsaak van besering was.*

- Ongeluk gedurende sport
- Ongeluk gedurende onspanningsaktiwiteite
- Ongeluk gedurende werk
- Verkeersongeluk
- Besering as gevolg van geweld bv. *skietwond*
- 'n Val van minder as 1 meter
- 'n Val van meer as 1 meter
- Ander oorsaak van besering: □.....

**Oorsaak a.g.v. siekte:**

*Merk als wat van toepassing is*

- Degenerasie van die spinalekolom
- Gewas - Goedaardig
- Gewas – kwaadaardig (kanker)
- Vaskulêre problem (bv.bloedloosheid, bloedvloeïing, misvorming)
- Infeksie ( bv. Bakterieel, virus)
- Ander: □.....

14. **Dui asseblief so presies as moontlik die datum aan waarop die spinale koordbesering plaasgevind het.**

DD / MM / JJJJ

□□/□□/□□□□

## Energie en gevoelens

Hierdie vrae gaan oor hoe u voel en hoe dit met u die laaste 4 weke gesteld was. Gee vir elke vraag die een antwoord wat die naaste beskryf hoe u gevoel het.

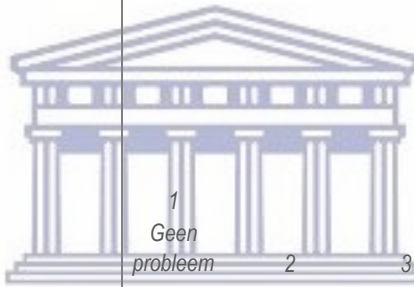
<b>Hoeveel van die tyd <u>gedurende die laaste 4 weke</u></b>	<i>Al die tyd</i>	<i>Meeste van die tyd</i>	<i>Sommige tye</i>	<i>Baie min</i>	<i>Nooit nie</i>
15. Het u lewenslustig gevoel?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Was u baie senuweeagtig?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Was u so terneergedruk dat niks vir u wou werk nie?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Het u kalm en rustig gevoel?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Was u energiek?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Was u terneergedruk en depressief?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Het u afgemat gevoel?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Was u gelukkig?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Was u moeg?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



## Gesondheidsprobleme

Beoordeel asseblief in hoe 'n mate die volgende gesondheidsprobleme die laaste 3 maande vir u probleme besorg het. As u die bepaalde gesondheidsprobleem ondervind het, dui ook aan of u behandeling daarvoor ontvang het, of nie (byvoorbeeld, medikasie ontvang of behandeling ontvang van dokter of ander gesondheidsprofessioneel).

	1 Geen probleem	2	3	4	5 Uiterste probleem	Het u behandeling daarvoor gekry?
<b>24. Slaapprobleme</b> <i>Bv. Dit sluit in problem om aan die slaap te raak, om deurnag te slaap en om vroeg wakker te raak.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nee
<b>25. Probleme met ontlasting</b> <i>Bv. Dit sluit in diarree, stoelgang onbeheerstheid (ongelukke) en konstipasie.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nee
<b>26. Urinekanaalinfeksie</b> <i>Bv. Dit sluit in nier- en blaasinfeksies.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nee
<b>27. Blaasdisfunksie</b> <i>Bv. Dit sluit in swak van blaas of nierstene, urinelekkasie, terugtrek van urine.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nee
<b>28. Seksuele disfunksie</b> <i>Bv. Dit sluit in disfunksie in seksuele opwekking, -ereksie en bereiking van orgasme.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nee
<b>29. Kontrakture</b> <i>Dit is die limitasie (tekortkoming) rakende die reikwydte van die beweging van spiere.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nee
<b>30. Spiersametrekkings, spastisiteit</b> <i>Dit verwys na onbeheerste, rukkerige spierbewegings, soos bv. onbeheerste spiertrekkings en krampe.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nee
<b>31. Druksere ,Bedsere</b> <i>Hierdie ontwikkel as 'n veluitslag of rooiheid van die vel en ontwikkel verder as 'n geïnfecteerde seer.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nee

<p><b>32. Respiratoriese Probleme ( Asemhalingsprobleme )</b></p> <p><i>Simptome van respiratoriese infeksies of –probleme sluit in moeilikheid met asemhaling en toenemende uitskeidings.</i></p>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nee
<p><b>33. Beserings veroorsaak deur die gebrek aan sensasie</b></p> <p><i>Bv. Dit sluit in brandwonde opgedoen deur warm vloeistof in die skoot te dra of deur te na aan die vuur of die verw warmer te sit.</i></p>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nee
<p><b>34. Sirkulasieprobleme</b></p> <p><i>Dit sluit in geswelde are van voete, bene en hande, of die ontwikkeling van bloedklonte.</i></p>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nee
		
<p><b>35. Outonomiese disrefleksia</b></p> <p><i>Simptome is skielike styging in bloeddruk en sweet, vlekke of puisies op die vel, pupiluitsetting en hoofpyn.</i></p>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nee
<p><b>36. Posturale lae bloeddruk</b></p> <p><i>Dit veroorsaak 'n sterk sensasie van lighoofdigheid na 'n verandering van posisie as gevolg van 'n skielike daling in die bloeddruk.</i></p>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nee
<p><b>37. Pyn</b></p> <p><i>Om pyn in jou daaglikse lewe te ondervind</i></p>	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>	<input type="radio"/> Ja <input type="radio"/> Nee

**38. Beoordeel asseblief u pynvlak deur die nommer wat u pyn die beste beskryf die laaste week, te omsirkel.**

*Geen pyn*

*Die ergste pyn wat u u kan voorstel*



- 0
- 1
- 2
- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10

**39.** Noem asseblief vyf addisionele gesondheidsprobleme wat u verder pla:

Geen addisionele gesondheidsprobleme om te verklaar

 .....

 .....

 .....

 .....

 .....

**40.** Dui asseblief u huidige “rookstatus” aan:

- Nog nooit gerook nie
- 'n voormalige roker
- Huidige roker (sluit geleentheidsroker in)

## Aktiwiteite en deelname

Die volgende gedeelte gaan oor probleme wat u in u lewe ondervind. Neem in aanmerking buide goeie sowel as die swak dae.

In die <u>laaste 4 weke</u> , in hoe 'n mate het u 'n problem geondervind om...	1 <i>Geen probleem</i>	2	3	4	5 <i>Uiterste probleem</i>
41. ... daaglikse roetine uit te voer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
42. ... stress te hanteer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
43. ... In hoe 'n mate besorg dinge wat met die hande en vingers gedoen moet word vir u probleme bv. om klein voorwerpe op te tel of om houers oop te maak?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
44. ... te kom waar u wil wees?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
45. ... publieke vervoer te gebruik?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46. ... privaatte vervoer te gebruik?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
47. ... na u gesondheid om te sien, gesond te eet, oefen of u medikasie te neem?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
48. ... u huishoudelike take klaar te maak?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
49. ... ander te versorg en van hulp te wees?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
50. ... met ander te interakteer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
51. ... met intieme verhoudings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
52. ... dinge vir ontspanning of plesier te doen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
53. ... word u kort van asem gedurende fisieke inspanning?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
54. Is u in staat om te ongesteund te sit?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<input type="radio"/> Nee					

<input type="radio"/> Ja → Hoeveel van 'n probleem is dit om vir lang periodes soos 30 minute te sit?	
<b>55. Is u in staat om ongesteund te staan?</b> <input type="radio"/> Nee <input type="radio"/> Ja → Hoeveel van 'n probleem is dit om vir lang periodes soos 30 minute te staan?	<input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/> <input type="radio"/>

Hierdie vrae gaan oor u vermoë om aktiwiteite wat basiese mobiliteit (beweeglikheid) vereis, te kan doen. Kies die respons wat u vermoë om sonder die hulp van ander, maar met hulp van die toerusting en apparate wat u normaalweg gebruik, die beste beskryf, bv. verplasinplank, hyskraan, hospitaalbed.

Is u in staat om...	<i>Geen moeilikhed</i>	<i>Kleine moeilikhed</i>	<i>Met sommige moeilikhed</i>	<i>Met baie moeilikhed</i>	<i>Nie in staat om uitvoer nie</i>
56. ... vanaf 'n posisie waar u op u rug lê, sonder hulp op te staan?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
57. ...'n swaar deur oop te stoot?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
58. ... vanaf 'n sittende posisie op die kant van die bed te verskuif deur op u rug te gaan lê?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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## Onafhanklikheid van aktiwiteite van die daaglikse lewe

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Vir elke item moet u die stelling aftik wat u huidige toestand ten beste reflekteer. Lees asseblief die teks sorgvuldig deur en kies slegs een boks in elke seksie.

### 59. Eet en drink

- Ek benodig kunsmatige voeding of 'n maagbuis.
- Ek benodig algehele bystand met eet/ drink.
- Ek benodig gedeeltelike bystand met eet/ drink of om met aanpassingsapparate aan- of uit te trek.
- Ek eet/ drink onafhanklik, maar benodig aanpassingsapparate of hulp met die sny van voedsel, skink van drankies en oopmaak van houers.
- Ek eet/ drink onafhanklik sonder hulp of aanpassingsapparate.

### 60. Was van bo-lyf en hoof

*Die was van die bolyf en hoof sluit in seepsmeer en die afdroog en die gebruik van 'n waterkraan.*

- Ek benodig totale bystand.
- Ek benodig gedeeltelike bystand.
- Ek is onafhanklik maar benodig aanpassingsapparate of spesifieke toerusting (bv. balke, stoel)
- Ek is onafhanklik en benodig geen aanpassingsapparate of spesifieke toerusting.

### 61. Was van onderlyf

*Die was van die onderlyf sluit in seepsmeer en die afdroog en die gebruik van 'n waterkraan.*

- Ek benodig totale bystand.
- Ek benodig gedeeltelike bystand.
- Ek is onafhanklik maar benodig aanpassingsapparate of spesifieke toerusting (bv. balke, stoel)
- Ek is onafhanklik en benodig geen aanpassingsapparate of spesifieke toerusting.

### 62. Klee ( aantrek) van die bolyf

*Die klee van die bolyf sluit in die aan- en uittrek van klere soos T-hemde, bloese hemde, brassieres, skawe en ortose( bv. armspalse, nekstutte, korsette )*

- Maklik- om – aan- te- trek klere is klere sonder knope, ritssluiters en veters
- Moeilik- om- aan- te- trek klere is klere met knope, ritssluiters en veters

- Ek benodig algehele bystand.
- Ek benodig gedeeltelike bystand, selfs met maklik- om- aan- te- trek klere.
- Ek benodig nie hulp met maklik- om – aan- te- trek klere nie, maar gebruik aanpassingsapparate of spesifieke toerusting



- Ek is onafhanklik met maklik- om- aan- te- trek klere, maar benodig hulp of aanpassingsapparate of 'n spesifieke omgewing met moeilik- om- aan- te- trek klere.
- Ek is heeltemal onafhanklik.

**63. Klee van die onder gedeelte van die liggaam**

*Die aantrek van die onder gedeelte van die liggaam sluit in die aan- en uittrek van klere soos kortbroeke, broeke, skoene sokkies, gordels en ortoses soos 'n beenspalk*

- Maklik- om – aan- te- trek klere is klere sonder knope, ritssluiters en veters
- Moeilik- om- aan- te- trek klere is klere met knope, ritssluiters en veters

- Ek benodig algehele bystand.
- Ek benodig gedeeltelike bystand, selfs met maklik- om- aan- te- trek klere.
- Ek benodig nie hulp met maklik- om – aan- te- trek klere nie, maar gebruik aanpassingsapparate of spesifieke toerusting
- Ek is onafhanklik met maklik- om- aan- te- trek klere, maar benodig hulp of aanpassingsapparate of 'n spesifieke omgewing met moeilik- om- aan- te- trek klere.
- Ek is heeltemal onafhanklik.

**64. Selfversorging**

*Bv. aktiwiteite soos om hande te was, tande te borsel, hare te borsel, te skeer en grimering te doen.*

- Ek benodig volle hulp.
- Ek benodig gedeeltelike hulp.
- Ek is onafhanklik met aanpassingsapparate.
- Ek is onafhanklik sonder aanpassingsapparate.

**65.**

**Blaashantering**

*Dink asseblief aan die manier hoe u u blaas verlig.*

**D. Gebruik van 'n interne kateter**

- Ja → *Gaan asseblief na vraag nommer 66*
- Nee → *Antwoord asseblief B and C.*

**E. Onderbroke katetergebruik**

- Ek benodig algehele hulp
- Ek doen dit self met bystand.
- Ek doen dit self sonder bystand.
- Ek gebruik dit nie

**F. Die gebruik van eksterne dreineringsinstrumente** *bv. kondoomkateter, luiers, sanitêre doeke*

- Ek benodig algehele bystand
- Ek benodig gedeeltelike bystand
- Ek gebruik dit sonder bystand
- Ek is selfbeheerst met uriene en gebruik geen dreineringsinstrument nie.

**66. Beheer van ontlasting**

**A. Het u hulp met ontlasting nodig (bv om 'n setpil te gebruik)?**

- Ja
- Nee

**B. Ek ontlas...**

- Onreëlmatig of weinig (minder as een keer in drie dae)
- Gereeld (eenkeer of meer in drie dae)

**C. Ontlastingsonbeheertheid (ongelukkies) vind plaas .....**

- Daaglik
- 1-6 times keer per week
- 1-4 keer elke maand
- Minder as een keer per maand
- Nooit

**67. Toiletgebruik**

*Dink asseblief aan die gebruik van die toilet, die was van jou genetalieë en hande, die aan- en uittrek van klere en die gebruik van sanitêre doekies en luiers..*

- Ek benodig algehele hulp
- Ek benodig gedeeltelike hulp
- Ek benodig gedeeltelike hulp, maar kan myself skoonmaak.
- Ek het nie hulp nodig nie, maar wel aanpassingsapparate (bv. balke) of spesiale omgewing (bv. rolstoeltoeganklike toilet)
- Ek benodig nie enige aanpassingsapparaat of spesiale omgewing nie.

**68. Watter van die volgende aktiwiteite kan u sonder hulp of elektroniese aparate doen?**

*Merk als wat van toepassing is*

- Draai u bolyf in die bed.
- Draai u onderlyf in die bed.
- Sit op in die bed.
- Doen armopstote in 'n stoel of rolstoel.
- Ek benodig hulp met al die aktiwiteite.

**69. Verplasings van die bed na die rolstoel.**

- Ek benodig algehele hulp
- Ek benodig gedeeltelike hulp, toesig en aanpassingsapparate (bv. skuifplank)
- Ek benodig nie hulp of aanpassingsapparate nie.
- Ek gebruik nie 'n rolstoel nie.

**70. Rondbeweeg oor gemiddelde distansies ( 10 tot 1000 meter)**

Ek gebruik 'n rolstoel om rond te beweeg, ...

- Ek benodig volle hulp.
- Ek benodig 'n elektriese rolstoel of gedeeltelike hulp om 'n gewone rystoel te opereer.
- Ek opereer my gewone rystoel onafhanklik.

Ek stap gemiddelde distansies en ek...

- Benodig toesig terwyl ek stap (met of sonder loopapparate).
- Loop met 'n loopraam of krukke, swaai vorentoe met beide voete.
- Loop met krukke of twee stoke deur een voet voor die ander te plaas.
- Loop met een stok.
- Loop met 'n beenortose ( bv 'n beenspalk).
- Loop sonder loophulpmiddels.



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71. **Wat was die benaming of title van u hoofberoep voor u spinale koordbesering?**
- Ek was werkloos voor my besering.  
Die naam of title van my hoofberoep was soos volg: *(wees asseblief so spesifiek as moontlik bv nie net klerk nie, maar bankklerk, nie net bestuurder nie, maar verkoopsbestuurder).*
- .....
72. **Het u beroepsrehabilitasie dienste ontvang na u spinale koordbesering?**  
*bv. beroepsvoorsligting, beroepsheropleiding, werkvaardigheidsopleiding*
- Ja  
 Nee
73. **Na u ontslag van u aanvanklike binne- pasiënt rehabilitasie, hoe lank het dit geneem voor u u betaalde werk hervat het?**
- Ek het nooit na aanvanklike binne- pasiënt rehabilitasie weer gewerk nie.  
 Onmiddellik na aanvanklike rehabilitasie  
 Ek het my werk hervat na ..... jare en ..... maande
74. **Ontvang u tans 'n ongeskiktheidspensioen of 'n gelykstaande ongeskiktheidsvoordeel?**
- Ja  
 Nee
75. **Wat is u huidige werksituasie?**  
*Merk als wat van toepassing is*
- Werk vir 'n loon of 'n salaries vir 'n werkgewer vir ..... ure per week  
 Werk vir 'n loon vir 'n werkgewer vir ..... ure 'n week, maar tans met siekteverlof vir meer as 3 maande.  
 Selfdiensname, werk vir ..... ure 'n week.  
 Werk as 'n onbetaalde familielid ( werk in familiebesigheid)  
 Huishoudster / Huishouer  
 Student  
 Werkklose  
 Afgetree weens gesondheid  
 Afgetree weens ouderdom  
 Ander, spesifiseer asseblief: .....
76. **Is u tans betrokke in betaalde werk?**
- Ja  
 Nee → *gaan asseblief na vraag 84*
77. **Wat is die benaming of die title van u huidige hoofberoep?**  
*Wees asseblief so spesifiek as moontlik bv. nie slegs klerk, maar bankklerk; nie slegs bestuurder, maar verkoopsbestuurder*
- .....
78. **Wil u meer, minder, of dieselfde hoeveelheid ure soos tans werk?**
- Meer ure  
 Minder ure

	1 Geen probleem	2	3	4	5 Uiterse probleem
<input type="radio"/> Dieselfde aantal ure					
79. Hoeveel van 'n probleem is dit om dit wat van u by die werk verwag word, gedaan te kry?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
80. Hoeveel van 'n probleem is dit om toegang tot u werkplek te verkry? <i>bv. toegang tot die gebou, u kantoor of die toilette</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Heeltemal	Tot 'n groot mate	Tot 'n mate	Tot 'n mindere mate	Glad nie	Ek het nie so 'n behoefte nie
81. Beskik u oor die hulpverleningswerksapparate wat u nodig het om te werk? <i>bv. hulpverleningsrekenaarapparate, arm- of handstutte of kunsmatige ledemate.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Die volgende vrae hou verband met u huidige beroep of werk: Vir elkeen van die volgende stellings, dui asseblief aan of u daarmee ten volle saamstem, saamstem, nie saamstem nie of sterk daarmee verskil.

	Stem ten volle saam	Stem saam	Stem nie saam nie	Verskil sterkliks
82. Ek ontvang die erkenning wat ek vir my werk verdien.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
83. Al my harde werk en prestasies in ag geneem, is my vergoeding billik. → gaan asseblief na vraag 87	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

84. Sal u daarvan hou om `n betaalde werk te bekom?

- Ja
- Nee

85. Voel u in staat om betaalde werk te kan verrig?

- Ja, vir 1 – 11 ure `n week
- Ja, vir 12 – 20 ure `n week
- Ja, vir meer as 20 ure `n week
- Nee, glad nie

86. Om watter redes werk u tans nie?

*Merk als wat van toepassing is*

- Gesondheidstoestand of gestremdheid
- Besig met opvoedings- en werksopleiding
- Persoonlike familie-verantwoordelikheid
- Vind nie geskikte werksgeleentheid nie
- Weet nie waar en hoe om werk te vind nie
- Het nie die finansiële behoefte nie
- Ouer of eggenoot weier dat ek werk
- Onvoldoende vervoerdienste
- Ontoeganklikheid tot moontlike werksplekke *bv. toegang tot die gebou, u kantoor of die toilette*
- Kom hulpverleningsapparate kort.
- Vrees dat u u ongeskiktheidsvoordeel sal verloor? *bv. pensioen, gesondheidsversekeringsdekking*
- Ek wil nie werk nie
- Ander, spesifiseer asb.: *.....*

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## Omgewingsfaktore

In die daagse lewe word ons aan talle eksterne invloede of omgewingsfaktore blootgestel. genaamd die sogenaamde omgewingsfaktore. Dit kan jou lewe vergemaklik of bemoeilik. Dink aan die laaste 4 weke en beoordeel asseblief hoe hierdie omgewingsfaktore u deelname in die gemeenskap/ samelewing beïnvloed het.

	Nie van toepasig	Geen invloed	Maak my lewe tot n mate moeilik	Maak my lewe baie moeilik
87. <b>Afwesigheid of onvoldoende toeganklikheid tot openbare plekke</b> <i>bv. ontoeganklike publieke geboue,parke</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
88. <b>Afwesigheid of onvoldoende toegang tot vriende en familie se huise.</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
89. <b>Swak klimaatstoestande</b> <i>bv. weer,seisoen,temperatuur,humiditeit</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
90. <b>Negatiewe gesindhede van die gemeenskap teenoor gestremde persone</b> <i>bv. vooroordeel, stigma, onkunde</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
91. <b>Negatiewe gesindhede van u gesin an ander familie teenoor u gestremdheid</b> <i>bv. vooroordeel, gebrek aan ondersteuning, oorbeskerming</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
92. <b>Negatiewe gesindhede van u vriende teenoor u gestremdheid</b> <i>bv. vooroordeel, gebrek aan ondersteuning, oorbeskerming</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
93. <b>Negatiewe gesindhede van u bure, kennisse en kollegas teenoor u gestremdheid</b> <i>vooroordeel, gebrek aan ondersteuning, oorbeskerming</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
94. <b>Gebrek aan- of onvoldoende ondersteuningstegnologie om oor kort afstande te beweeg</b> <i>gebrek aan- of onvoldoende hulp om trappe te klim, loop aparate, rolstoel</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
95. <b>Gebrek aan of onvoldoende aanpassing van vervoer oor lang afstande</b> <i>bv. tekort aan aangepaste motor, publieke vervoer wat moeilik gebruik word.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
96. <b>Tekort aan of onvoldoende verpleegsorg en ondersteunende dienste</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	<i>bv. tekort aan of onvoldoende gesondheidsorg by die huis of persoonlike hulp</i>				
97.	<b>Gebrek aan of onvoldoende medikasie en mediese bystand en -voorrade</b> <i>bv. gebrek aan of onvoldoende kateters, ontsmettingsmiddels, spalke, kussings</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
98.	<b>Moeilike finansiële posisie</b> <i>bv. tekort aan geld</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
99.	<b>Gebrek aan- of tekort aan kommunikasieapparate</b> <i>bv. gebrek aan of onvoldoende skryfapparate, rekenaar, telefoon, muis</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
100.	<b>Gebrek aan of onvoldoende staatsdienste</b> <i>bv. gebrek aan of onvoldoende ongeskiktheidsversekering of ander voordele</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### Gesondheidsorg dienste

101. Wie was die gesondheidsorg verskaffers wat u besoek het, of wie u huis besoek het, in die laaste 12 maande?

*Merk als wat van toepassing is*

- Primêre sorg dokter/ algemene praktisyn
- Rehabilitasie dokter / spinale koord beseringsdokter
- Ander spesialisasie dokter e.g., Chirurg, ginekoloog, psigiater, oogaarts
- Verpleegster of vroedvrou
- Tandarts
- Fisioterapeut
- Chiropraktisyn
- Arbeidsterapeut
- Sielkundige
- Tradisionele geneeskundige e.g., naturopaat, acupuncturist, kruiedokter
- Apteker
- Huis gesondheidsorg werker
- Ander, spesifiseer asseblief.....
- Ek het geen gesondheidsorgvoorsiener gedurende die laaste 12 maande besoek nie.

102. Oor die afgelope 12 maande hoeveel keer was u 'n pasiënt in 'n hospital, rehabilitasiefasiliteit of 'n ander versorgingsfasiliteit vir ten minste een nag?

..... (aantal kere)

Hoe sal u die volgende beoordeel na aanleiding van u laaste besoek aan 'n gesondheidsorgvoorsiener?


Baie goed      Goed      Nie goed of swak nie      Swak      Baie swak



103	...u ervaring om met respek behandel te word.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
104	...hoe duidelik die gesondheidsorgvoorsieners dinge verduidelik.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
105	... u ervaring van u betrokkenheid in die besluite wat geneem word rakende u behandeling.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

- 106 In die afgelope 12 maande, het u gesondheidsorg benodig, maar dit nie ontvang nie?
- Nee
  - Ja. Watter redes verduidelik ten beste waarom u nie die gesondheidsorg ontvang het wat u nodig gehad het nie?

*Merk als wat van toepassing is*

- Ek kon nie die besoek bekostig nie.
- Daar was geen diens nie.
- Geen vervoer beskikbaar nie.
- Ek kon nie die vervoerkoste bekostig nie.
- Ek was voorheen swak behandel.
- Ek kon nie die tyd afneem nie of het ander verpligtinge gehad.
- Die gesondheidsorgvoorsiener het 'n tekort aan geneesmiddels en toerusting gehad.
- Die gesondheidsorgvoorsiener se vaardighede was ontoereikend.
- Ek het nie geweet waarheen om te gaan nie.
- Ek het probeer, maar is gesondheidsorg geweier.
- Ek het gedink dat ek nie siek genoeg was nie.
- Ander, spesifiseer asseblief  .....

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	Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied
107 In die algemeen, hoe tevrede is u met die gesondheidsorgdienste in u area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Persoonlike faktore

Die volgende vrae handel oor hoe u uself sien.

	1 <i>Glad nie</i>	2	3	4	5 <i>Ten volle</i>
108 In hoe 'n mate is u seker dat u oor die vermoë beskik om u sin te kry as iemand u sou teenstaan?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
109 Hoe seker is u dat u in staat is om onverwagte gebeurlikhede effektief te kan hanteer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
110 Hoe seker is u dat u kontak sal kan behou met die mense wat vir u belangrik is?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
111 Hoe seker is u dat u goeie gesondheid kan handhaaf?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
112 Dink jy dat jou spinale koordbesering u 'n sterker persoon gemaak het?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
113 Bekommer u u oor wat met u in die toekoms kan gebeur? <i>Bv. dink aan om na u self om te sien of om 'n oorlas vir ander te wees.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
114 Voel u dat u in staat is om u drome, verwagtinge en wense te verwesenlik?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
115 Is u in staat om belangrike besluite in die lewe te kan maak? <i>bv. om te besluit waar en by wie om te woon en hoe om u geld te spandeer.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
116 Voel u dat ander u insluit as u met hulle is?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
117 Het u in die laaste 12 maande enige groot negatiewe lewensgebeurlikheid beleef, <i>bv. 'n ernstige konfliktsituasie met ander of egskeiding of die dood van 'n geliefde.</i>	<input type="radio"/> Nee <input type="radio"/> Ja, spesifiseer asseblief: <input type="text"/>				

## Lewenskwaliteit en algemene gesondheid

Die volgende vrae behels u beoordeling van u kwaliteit van lewe oor die laaste 14 dae. Dink asseblief aan u lewe gedurende die laaste 14 dae. Hou asseblief die volgende in gedagte: u standaard, verwagtinge, genietinge en verse.

In die laaste 14 dae	Baie swak	Swak	Nie swak of goed nie	Goed	Baie goed
118. Hoe sal u u kwaliteit van lewe beoordeel?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
119. In hoe 'n mate is u tevrede met u gesondheid?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
120. In hoe 'n mate is u tevrede met u vermoë om u daaglikse aktiwiteite uit te voer?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
121. In hoe 'n mate is u tevrede met uself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
122. In hoe 'n mate is u tevrede met u persoonlike verhoudings?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
123. In watter mate is u tevrede met u lewensomstandighede?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

124. Hoe sal u u algemene gesondheid beskryf?

- Puik
- Baie goed
- Goed
- Gemiddeld
- Swak

125. In vergelyking met 'n jaar te vore, hoe sal u tans u algemene gesondheid beskryf?

- Baie beter
- 'n bietjie beter
- Feitlik dieselfde
- Ietwat verswak
- Baie verswak

**Ons bedank u grootliks vir u deelname  
in die InSCI opname!**



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## Appendix 10: IsiXhosa InSCI Questionnaire



# International Spinal Cord Injury Survey (InSCI)



*The first worldwide survey  
on community-dwelling persons with spinal cord injury.*

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*Countries all over the world take part in this initiative to capture the experience of living with spinal cord injury by asking those who know best: persons with spinal cord injury.*

*A collaboration of*





Dear participant

***Welcome to the InSCI survey, we are very happy to have you on board!***

InSCI is the first worldwide survey on community-dwelling persons with spinal cord injury. Countries all over the world take part in this initiative to capture the experience of living with spinal cord injury by asking those who know best: persons with spinal cord injury.

Please fill in the questionnaire as completely as possible and don't leave any questions unanswered. There is no right or wrong and no good or bad answer. It is important that you answer spontaneously and decide which response best applies to your personal situation.

You can also complete the questionnaire online at [[www.insci.com](http://www.insci.com)]. Please login with your InSCI-ID and your personal password:

Your InSCI-ID is: #####

Your personal password is: #####



We guarantee that your data is protected with the highest security standards. No personal data will be handed out to third persons outside the study center. All questionnaires are anonymized by a unique identification number (InSCI-ID) and there is no personal information such as name or address on the paper or online questionnaire.

In case you have any question or need support in questionnaire completion, we are happy to help. Please send us an email at [contact@en.insci.network](mailto:contact@en.insci.network) or contact our toll-free InSCI-helpline at 0700 523 696 631.

Thank you again for your commitment!

Your InSCI-Team [*may add names of local PIs*]

1. Nceda uchaze isini sakho:

- Indoda
- Ibhinqa

2. Ingaba wawuzelwe ngoluphi usuku, inyanga nonyaka?

USUKU/ INYANGA/ UNYAKA

□□/□□/□□□□

3. Ingaba wawuzalelwe kweliphi ilizwe?





 .....

4. Ingaba utshatile?

- Anditshatanga
- Nditshatile
- Siyahlalisana okanye liqabane
- Wahlukene okanye uqhawule umtshato
- Uhlolokazi

5. Ngubani ohlala nawe ekhaya?

*Krwela zonke ezingenayo*

- Ndihlala ndodwa
- Nabantwana abangaphantsi kweminyaka eli-14 ubudala, inani labo:  .....
- Ulutsha oluphakathi kweminyaka eli-14 neli-18 ubudala, inani lalo:  .....
- Abantu abaphakathi kweminyaka eli-18 nama-64 ubudala, inani labo:  .....
- Abantu abangaphezulu kwama-64 ubudala, inani labo:  .....
- Ndihlala kwindawo ekhethekileyo *umz. ikhaya labantu abadala, ikhaya lonyango ngoomongikazi*

6. Ingaba uyalufumana uncedo ngezinto zakho ozenzayo zemihla ngemihla ekhaya okanye ngaphandle?

- Hayi
- Ewe, ngaba bantu balandelayo:

*Krwela zonke ezingenayo*

- Usapho
- Abahlobo
- Abaqeqeshiweyo okanye abancedisi abahlawulwayo

7. Lithini ibakala eliphezulu lemfundo oligqibileyo? *[iintlobo ezikhethekileyo ngokwelizwe]*

- Eliphantsi
- Elisezantsi
- Eliphezulu
- Elingaphaya kweSekondari
- Efutshane yamaziko aphezulu
- Isidanga okanye okulinganayo

- Imastazi okanye okulinganayo
- Okunye, kuchaze: ✍️ .....

**8. Mingaphi iminyaka yemfundo okanye eyoqeqesho othe walugqiba?**

Iminyaka yemfundo okanye eyoqeqesho ngaphambi kokuba ufumane ingozi yomnqonqo: ✍️ ..... (Inani leminyaka)

Iminyaka yemfundo okanye eyoqeqesho emva kokuba ufumane ingozi yomnqonqo: ✍️ ..... (Inani leminyaka)

**9. Xa uthabathela ingqalelo bonke abantu ohlala nabo ekhayeni lakho abasebenzela umvuzo okanye intlawulo: ingaba ithini ingeniso iyonke yekhaya [ngaphambi, emva] kweerhafu ngenyanga umyinge?**

- < R1100 ngenyanga
- R1101 – R3000 ngenyanga
- R3001 –R4500 ngenyanga
- R4501 – R6000 ngenyanga
- R6001 –R9000 ngenyanga
- R9001 – R12000 ngenyanga
- R12001 – R20 000 ngenyanga
- R20001 – R3000 ngenyanga
- R30001 – R50000 ngenyanga
- > R500001

**10. Cinga ngale leli njengemele apho abantu bami khona e*[ilizwe]*.**

Kwincopho yeleli ngabo bantu abazizityebi – abo banemali eninzi, abo bafundileyo kwaye bakwimisebenzi ehlonitshwayo. Ezantsi ngabo bantu bahlupheke kakhulu – abo banemali encinane, imfundo ephantsi, kwaye bakwimisebenzi ejongelwe phantsi okanye abaphangeli. Xa usiya unyuka kwileli, uya kusondela kwabo bantu basencotsheni; xa usiya ezantsi, uya kuba kufutshane naba abasezantsi.

**Ingaba ungazibeka ndawoni wena kule leli?**

Nceda ufake u- **X** kwinqwanqwa apho wena unokuzibeka kulo ngoku ebomini bakho, xa uzithelekisa nabanye abantu *[kwilizwe lakho]*





11. Nceda uchaze inqanaba lomonzakalo kumnqonqo wakho:

- Ukufa amanqe (intshukumo nemvakalelo eqhekelileyo kumalungu angezantsi)
- Ukufa amalungu omzimba onke (ukungabikho okanye imvakalelo eyahlukileyo kwentshukumo okanye imvakalelo kwiingalo okanye imilenze)

12. Ingaba umonzakalo wakho ugqibelel okanye awugqibelelanga?


- Ugqibelele (andikwazi kuva nokushukumisa naliphi na elinye ilingu lomzimba ongezantsi kwale ndawo yomonzakalo)
- Awugqibelelanga (andikwazi ukuva nakushukumisa amanye amalungu omzimba ongezantsi kwale ndawo yomonzakalo)

13. Nceda ucacise ukuba yintoni unobangela womonzakalo wakho kumnqonqo

Okwenziwe yingozi:


*Jonga konke okungqameleneyo*

*Uumzekelo xa ujonga ibhokisi 'umonzakalo ngexesha lomsebenzi', nceda cacisa ukuba ingaba kukuwa okanye omnye unobangela wengozi.*

- Umonzakalo ngexesha lezemidlalo
- Umonzakalo ngexesha lolonwabo
- Umonzakalo ngexesha lomsebenzi
- Ingozi yemoto
- Umonzakalo ngenxa yobondlobongela (e.g., isilonda sokudutyulwa)
- Ukuwa ngaphantsi kwemitha enye
- Ukuwa ngaphezulu kwemitha enye
- Omnye unobangela womonzakalo:  .....

Unobangela osisifo:

*Krwela okubandakanyekayo*

- Ukuyekela komqolo
- Ithumba – elingenabungozi
- Ithumba – elinobungozi (umhlaza)
- Ingxaki yemithambo (umz., e.g., iskemiya, ukopha, ukungemi kakuhle)
- Ukusuleleka (umz., ibhokisi, iintsholongwane)
- Ezinye izifo:  .....

14. Nceda uchaze ngokuchanekileyo kangangoko ukuba wawenzakale ngawuphi umhla umnqonqo wakho:

USUKU/ INYANGA/ UNYAKA

□□/□□/□□□□

## Udlamko nemvakalelo

Lemibuzo imalunga nokuba waziva njani kwaye izinto zabanjani kuwe kwezi veki zine zidlulileyo. Nceda kumbuzo nganye unike impendulo iyeleleneyo nendlela oziva ngayo.

<b>Lixesha elingakanani kwezi <u>veki zine zidlulileyo</u> ...</b>	<i>Ngalo lonke ixesha</i>	<i>Amaxesha amaninzi</i>	<i>Ngelinye ixesha</i>	<i>Ixesha elincinci</i>	<i>Akukho xesha ndiziva njalo</i>
15. Ingaba uziva udlamkile?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Wakhe waxhalaba kakhulu?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Wakhe waziva udakumbile, ubone ukuba akukho nto inokwenza udlamke?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Ukhe waziva upholile kwaye useluxilweni? ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Ubukhe udlamke kakhulu?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Wakhe waziva udakumbile kwaye ubuthakathaka?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Uziva uphelelwa ngamandla?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Wakhe wonwaba?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Uziva udiniwe?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Ingxaki zempilo

Ngezi ngxaki zilandelayo zempilo, nceda uthethekelele ukuba ezi ngxaki zibe ziingxaki ezinjani kwezi nyanga zintathu ziggithileyo. Ukuba uthe wazifumana ezi ngxaki zempilo, nceda uphawule ukuba ingaba uthe wafumana unyanga okanye hayi (umzekelo ukusela amayeza okanye ukufumana unyango loogqirha okanye abanye abaqeqeshelwe ezempilo).

	1 <i>Akukho Ngxaki</i>	2	3	4	5 <i>Ingxaki enkulu</i>	<i>Ukhe/ wakhe wafumana unyango lwayo?</i>
<b>24. Ingxaki zokulala</b> <i>umzekelo, ingxaki zokwehla kobuthongo okanye ulala ubusuku bonke uvuke ekuseni kakhulu.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ewe <input type="radio"/> Hayi
<b>25. Ukuhambi kakuhle kwesisu</b> <i>umzekelo, urhudo, ungakwazi ukubamba ilindle ("ingozi") nokuqhina.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ewe <input type="radio"/> Hayi
<b>26. Usuleleko lomchamo</b> <i>Umzekelo, izintso okanye ukusuleleka kwesinyi</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ewe <input type="radio"/> Hayi
<b>27. Isinyi esingasebenzi kakuhle</b> <i>umzekelo, ukuzichamela ("iingozi"), isinyi okanye isinyi okanye amaqhuma kwizintso, ingxaki kwizintsho, umchamo ongavakali xa uphuma and umchamo ugcinakele.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ewe <input type="radio"/> Hayi
<b>28. Ukuphela kwemizwa kwezesondo</b> <i>umzekelo, ukuphelelwa yimizwa yesondo, ukuvukelwa, ubumanzi, nokufikelela kukwaneliseka ngokwesondo.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ewe <input type="radio"/> Hayi
<b>29. Isimo sokwehlisa okanye ukuqinisa izihlunu</b> <i>Oku kukungakwazi ukusebenzisi amalungu omzimba ngokupheleleyo kwimidibaniso yamalungu omzimba.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ewe <input type="radio"/> Hayi
<b>30. Inkantsi yezihlunu, ukuqinelwa zizihlunu</b> <i>Oku kubhekisa kwiintshukumo zezihlunu ezingalawulekileyo ezinjengokushuma</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ewe <input type="radio"/> Hayi

	<i>kwezihlunu ngokungawulekiyo okanye inkantsi yezihlunu.</i>						
<b>31.</b>	<b>Izilonda ngenxa yokuhlala ndawonye, amatyhungutyhungu</b> <i>Ezi zilonda zivela njengerhashalala yesikhumba okanye ububomvu kwaye isenokuqhubeka ibesisilonda esinobumdaka esingapholiyo.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ewe <input type="radio"/> Hayi
<b>32.</b>	<b>lingxako zokuphefumla</b> <i>limpawu neengxaki zokwasuleleka ziquka iingxaki zokuphefumla nokunyuka kwemikhunya.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ewe <input type="radio"/> Hayi
<b>33.</b>	<b>Umonzakalo obangelwe kukulahleka kwemvakalelo</b> <i>Umzekelo, izilonda zokutsha ezinololwelo olushushu okanye ukuhlala phantsi ixesha elide kufutshane nehitha okanye umlilo.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ewe <input type="radio"/> Hayi
<b>34.</b>	<b>lingxaki zokuhamba kwegazi</b> <i>Oku kuquka ukudumba kwemithambo, iinyawo, imilenze okanye izandla, okanye uukwenzeka kwamahlwili egazini.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ewe <input type="radio"/> Hayi  <i>Ukhe/ wakhe wafumana unyango lwayo</i>
		1 Akukho ngxaki	2	3	4	5 Ingxaki inkulu kakhulu	
<b>35.</b>	<b>Ukunyukelwa luxinizelelo lwegazi ngokukhawuleza</b> <i>limpawu zokhawuleza kunyuke uxinizelelo lwegazi nokubila, amabala kwisikhumba, iingongoma, ukungabini owexeshana nentloko ebuhlungu.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ewe <input type="radio"/> Hayi
<b>36.</b>	<b>Ukufutheka ngenxa yokuma ixesha elide</b> <i>Oku kuquka imvakalelo yokuba nesiyezi kulandela ukutshintsha isikhundla sokuma. Oku kubangelwa kukuhla koxinizele lwegazi.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ewe <input type="radio"/> Hayi
<b>37.</b>	<b>Intlungu</b> <i>Ukuba neentlungu kubomi bemihla ngemihla.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Ewe <input type="radio"/> Hayi

38. Nceda uthelekele intlungu yakho ngokuthi urhangqe inombolo echaza ngcono intlungu yakho xa ibiphezulu kule veki iphekileyo.



39. Nceda uchaze iingxaki zempilo ezongezekileyo ezintlanu ezikuthukuthezelayo:

- Akukho zingxaki zempilo zongezekileyo endinazo

 .....

 .....

 .....

 .....

 .....

40. Nceda uphawule isimo sakutshaya:

- Zange ndatshaya
- Ndakhe ndatshaya
- Ndiyatshaya ngoku (kuquka umntu otshaya ngelo xesha)

## Imisetyenzana nokuthatha inxaxheba

Eli candelo lilandelayo linge ngxaki ohlangabezana nazo ebomini bakho. Nceda thathela ingqalelo iintsuku ezimbi nezintle xa ucinga.

<b><u>Kwezi veki zine zidlulileyo,</u> kukangakanani ngokwengxaki othe wahlangabezana nayo...</b>	1 <i>Akukho ngxaki</i>	2	3	4	5 <i>Ingxaki enkulu</i>
41. ... ukuqhubeka nezinto zakho zosuku?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
42. ... ukumelana noxinzelelo lwakho?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
43. ...ukwenza izinto ezizakufuna usebenzise izandla zakho kunye neminwe, njengoku phakamisa izinto okanye ukuvula ikhonteyina?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
44. ...ukufikelela apho ufuna ukuya khona?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
45. ...ukusebenzisa izithuthi zikawonke-wonke?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46. ... ukusebenzisa isithuthi zabucala?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
47. ...ukujongana nempilo yakho,ukutya kakuhle, ukuzilolonga okanye ukusela amayeza akho?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
48. ...ukwenza umsebenzi wakho wasendlwini uwugqibe?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
49. ... ukunikeza uncedo okanye inkxaso kwabanye?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
50. ... ukunxibelelana nabanye abantu?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
51. ... ukuthandana?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
52. ... ukwenza izinto zokuphumla okanye ukuzonwabisa?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

53. ... ukuqhawukelwa ngumphefumlo xa uzilolonga?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
54. Uyakwazi ukuhlala phantsi ungaxhaswanga? <input type="radio"/> Hayi <input type="radio"/> Ewe → Ingaba kuyingxaki kangakanani ukuhlala phantsi ixesha elide njengma-30 emizuzu?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
55. Uyakwazi ukuma ungaxhaswanga? <input type="radio"/> Hayi <input type="radio"/> Ewe → Ingaba kuyingxaki kangakanani ukuma ixesha elide njengma-30 emizuzu?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Le mibuzo ibuza ngokukwazi kwakho ukwenza imisetyenzana equka ukuhambahamba. Khetha impendulo echaza ngcono ukwazi ukuzenzela izinto ngaphandle kokuncedwa ngomnye umntu kodwa usebenzisa izixhobo okanye ubuxhakaxhaka obukade ubusebenzisa (umz., iibhodi zokuthwala umntu, izinyusi iibhedi zesibhedlele).

Uyakwazi uku...	Ngaphandle kobunzima	Kunzima kancinci	Kunzinyana	Kunzima kakhulu	Uwukwazi
56. ... ukuphakama emgangathweni ukusuka phantsi xa ubulele ngomqolo?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
57. ukutyhala ucango olunzima luvuleke?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
58. ...ukusuka xa ubuhleli ecaleni kwebhedi ufuna ukucambalala ngomqolo?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Ukuzimela kwizinto ozenzayo ngosuku lwakho

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Kwinto nganye, nceda qwalasela ibhokisi emelene nenkcazelo echaza imeko yakho ngoku. Nceda ufunde okubhaliweyo ngononophelo kwaye ukrwele ibhokisi enye kwicandelo ngalinye.

### 59. Ukutya nokusela

- Ndinga ukutyiswa ngophayiphu abafakwa emqaleni okanye esisuswini
- Ndinga ukuncediswa xa ndisitya / ndiseka
- Ndinga ukuncediswa kancinane xa ndisitya / ndisela okanye ndifaka / ndikhulula izixhobo zokuncedisa
- Ndiyazityela / ndiyaziselela ngokwam, kodwa ndidinga izixhobo ezincedisa okanye uncedo ukusika ukutya, ukugalela isiselo okanye ukuvula izigcini kutya.
- Ndiyazityela / ndiyaziselela ngokwam ngaphandle kokuncediswa okanye izixhobo zokuncedisa

### 60. Ukuhlamba amantla omzimba nentloko

*Oku kuquka ukufaka isepu nokosula, nokusetyenziswa amanzi etepu.*

- Ndinga ukuncediswa kangangoko
- Ndinga ukuncediswa kancinane
- Ndiyazenzela kodwa ndidinga izixhobo ezincedisayo okanye izixhobo ezikhethekileyo (umz., izibonda, izitulo)
- Ndiyazenzela kwaye andidingi zixhobo zincedisayo okanye izixhobo ezikhethekileyo

### 61. Ukuhlamba umzimba ongezantsi

*Oku kuquka ukufaka isepu nokosula, nokusetyenziswa amanzi etepu.*

- Ndinga ukuncediswa kangangoko
- Ndinga ukuncediswa kancinane
- Ndiyazenzela kodwa ndidinga izixhobo ezincedisayo okanye izixhobo ezikhethekileyo (umz., izibonda, izitulo)
- Ndiyazenzela kwaye andidingi zixhobo zincedisayo okanye izixhobo ezikhethekileyo

### 62. Ukunxiba impahla kumzimba ongentla

*Oku kuquka ukunxiba nokukhulula iimpahla ezinjengezikipa, iiblawuzi, iihempe, iibhodi, iholi, okanye izixhasi-mzimba (umz. isixhasi-ngalo, isixhasi-ntamo, ikhosethi).*

- *Iimpahla ezinxibeka lula zezo zingenamaqhosha, ziziphu okanye iileyisi*
- *Iimpahla ezinxibeka nzima zinamaqhosha, iziziphu okanye iileyisi*
- Ndinga ukuncediswa kangangoko
- Ndinga ukuncediswa kancinane, nokuba ziimpahla ekulula ukunxiba
- Andidingi kuncediswa ngeempahla ekulula ukunxiba, kodwa ndidinga izixhobo ezincedayo okanye ezikhethekileyo
- Ndiyakwazi ukuzinxibela iimpahla ekulula ukuzinxiba kwaye ndidinga nje uncedo okanye izixhobo zoncedo okanye imeko ezikhethekileyo xa ndinxiba iimpahla elinzima ukuyinxiba
- Ndiyazinxibela ngokupheleleyo

### 63. Ukunxiba umzimba ongezantsi

*Oku kuquka ukunxiba nokukhulula iimpahla ezinjengooshoti, iibhulukhwe, iikawusi, iibhanti okanye izixhasi-mzimba (umz. isixhasi-mlenze).*

- *Iimpahla ezinxibeka lula zezo zingenamaqhosha, ziziphu okanye iileyisi*



- *Iimpahla ezinxibeka nzima zinamaqhosha, iziziphu okanye iileyisi*
- Ndinga ukuncediswa kangangoko
- Ndinga ukuncediswa kancinane, nokuba ziimpahla ekulula ukunxiba
- Andidingi kuncediswa ngeempahla ekulula ukunxiba, kodwa ndidinga izixhobo ezincedayo okanye ezikhethekileyo
- Ndiyakwazi ukuzinxibela iimpahla ekulula ukuzinxiba kwaye ndidinga nje uncedo okanye izixhobo zoncedo okanye iimeko ezikhethekileyo xa ndinxiba iimpahla elinzima ukuyinxiba
- Ndiyazinxibela ngokupheleleyo

#### 64. Ukuzicoca

*Umz., imisetyenzana enjengokuhlamba izandla nobuso, ukuxukuxa, ukukama, ukusheva, okanye ukuthambisa.*

- Ndinga uncedo kangangoko
- Ndinga uncedo kancinane
- Ndiyazenzela xa kukho izixhobo zokuncedisa
- Ndiyazenzela ngaphandle kwezixhobo zokuncedisa

#### 65. Ukulawula isinyi

*Nceda ucinge ngendlela okhupha ngayo umchamo kwisinyi.*

##### G. Ukusetyenziswa kwekhathitha efakwe ngaphakathi

- Ewe → *Nceda uye kumbuzo wama-66*
- Hayi → *Nceda uphendule u-B no-C.*

##### H. Ikhathitha yesiqabu

- Ndinga uncediso kangangoko
- Ndiyenza ngokwam kodwa ndincediswa (ukuzifaka ikhathitha)
- Ndiyenza ngokwam kungekho luncedo (ukuzifaka ikhathitha)
- Andiyisebenzisi

##### I. Ukusetyenziswa kwesixhobo sokudontsa sangaphandle .(umz. ikhathitha yekhondom, iinapkeni )

- Ndinga uncedo kangangoko ukuwasebenzisa
- Ndinga uncedo kancinane ukuwasebenzisa
- Ndiwasebenzi ngaphandle koncediso
- Ndiyawabamba umchamo kwaye andisebenzisi zixhobo zokudontsa zangaphandle

#### 66. Ukulawula ukuzithuma

##### D. Ingaba udinga uncedo kulawulo lokuzithuma (umz. ukufaka amayeza ngaphantsi)?

- Ewe
- Hayi

##### E. Ukuzithuma kwam...

- akwenzeki rhoqo okanye kuhlale kuhlale kwenzeke (ngaphantsi kwesinye ngeentsuku ezi-3)
- rhoqo (kanye neentsuku ezi-3 okanye ngaphezulu)

##### F. Ukuzithuma okungalawulekileyo (“iingozi”) kwenzeka ...

- Ntsuku zonke
- Kanye ukuya kwisithandathu ngeveki
- Kanye ukuya kwisine ngenyanga
- ngaphantsi kwesinye ngenyanga
- Zange kwenzeka

**67. Ukusebenzisa ithoyilethi**

*Nceda ucinge ngokusebenzisa ithoyilethi, ukuhlamba kummandla wangaphantsi nezandla, ukunxiba nokukhulula impahla, nokusebenzisa amanapkeni.*

- Ndinga uncedo kancinane kwaye andikwazi ukuzicoca ngokwam
- Ndinga uncedo kancinane kodwa ndikwazi ukuzicoca ngokwam
- Andidingi luncedi kodwa ndidinga izixhobo zonediso (umz. izibonda) okanye imeko ekhethekileyo (umz. isitulo esifikelelayo ethoyilethi)
- Andidingo naluphi na uncedo, izixhobo zokuncedisa okanye imeko ekhethekileyo

**68. Yeyiphi kule misetyenzana ilandelayo ongakwazi ukuyenza ngaphandle kokuncediswa okanye izincedisi zombane?**

*Krwela konke okungasebenza*

- Ukuguqula umzimba wakho ongentla xa usebhedini
- Ukuguqula umzimba wakho ongentla xa usebhedini
- Ukuhlala ebhedini
- Ukuzinyusa uhleli esitulweni okanye kwisitulo esinamavili
- Akukho, ndidinga ukuncediswa kuyo yonke lemisetyenzana

**69. Ukusuka ebhedini ukuya esitulweni esihambayo**

- Ndinga uncedo kangangoko
- Ndinga uncediso kancinane, ukunakekelwa okanye izixhobo zokuncedisa (umz. ibhodi etshibilizayo)
- Andidingi naluphi na uncedo okanye izixhobo ezincedisayo
- Andidingi kusebenzisa isitulo esihambayo

**70. Ukuhambahamba imigama emifutshane (iimitha ezi-10 ukuya kwi-100)**

*Ndisebenzisa isitulo esihambayo. Ukuhambahamba, ...*

- Ndinga uncediso kangangoko
- Ndinga isitulo esizihambelayo sombane okanye uncediso oluncinane ukusebenzisa isitulo esihambayo
- Ndiyazenzela yonke into kwisitulo esihambayo

*Ndihamba imiganyana ephakathi kwaye...*

- ndidinga unakekelo ngelixa ndihambayo (kukho okanye kungekho zincedisi zokuhamba)
- ndihamba ngesakhelo sokuhamba okanye iintonga zokuhamba, ndijula imilenze yomibini ukuyisa phambili ngexesha
- ndihamba ngeentonga okanye ikheyini ezimbini, ndibeka unyawo olunye phambi kolunye
- ndihamba ngekhayini enye
- ndihamba ngesixhasi-mlenze kuphela (umz. izixhasi-mlenze)
- ndihamba ngaphandle kwezincedisi

71. Ingaba belisithini igama okanye isikhundla somsebenzi wakho obungundoqo ngaphambi komonzakalo kumnqonqo?
- Bendingenamsebenzi ngaphambi komonzakalo kumnqonqo.
  - Igama okanye isikhundla somsebenzi wam ongundoqo ibi (nceda uchaze ngqo kangangoko, umz. ungathi u'mabhalana' kodwa uthi 'umabhalana ebhankini', ungathi u'mphathi' nje kodwa yithi 'umphathi weentengisi'):
- .....*
72. Ingaba uthu wafumana iinkonzo zovuselelo ngokomsebenzi emva komonzakalo womnqonqo?  
*umz. iingcebiso ngezomsebenzi, uqeqesho kwakhona kwezomsebenzi, uqeqesho kwizakhono zomsebenzi*
- Ewe
  - Hayi
73. Emva kokuba ukhutshiwe kwicandelo labavuselelwa bengaphakathi lokuqala, ingaba ikuthabathe ixesha elingakanani ngaphambi kokuba uqale or ubuyele kumsebenzi ohlawulwayo?
- Andizange ndasebenza emva kokuvuselelwa kwangaphakathi kokuqala
  - Nje emva kokuvuselelwa kwangaphakathi kokuqala
  - Ndibuyele emsebenzini emva kweminyaka e *.....* neenyanga ezi *.....*
74. Ingaba ufumana ipenshini yokonzakala okanye esinye nje isibonelelo somonzakalo?
- Ewe
  - Hayi
75. Ingaba ithini imeko yakho yokusebenza ngoku?  
*Krwela konke okungasebenza*
- Ndisebenzela umvuzo kumqeshi iiyure ezi *.....* ngeveki
  - Ndisebenzela umvuzo kumqeshi iiyure ezi *.....* ngeveki, kodwa ngoku ndikwikhefu lokugula ngaphezu kweenyanga ezintathu
  - Ndiyazisebenzela, ndisebenza iiyure ezi *.....* ngeveki
  - Ndisebenza njengelungu losapho elingahlawulwayo (umz. ukusebenza kwishishini losapho)
  - Umfazi ogcina ikhaya / indoda egcina ikhaya
  - Umfundi
  - Andiphangeli
  - Ndidla umhlalaphantsi ngenxa yokugula
  - Ndidla umhlalaphantsi ngenxa yobudala
  - Enye, nceda uchaze: *.....*
76. Ingaba wenza umsebenzi ohlawulayo?
- Ewe
  - Hayi → *Nceda ugqithele kumbuzo wama-84*
77. Ingaba lithini igama okanye isikhundla somsebenzi wakho ongundoqo?  
*Nceda ucacise kangangoko, umz. ungathi u'mabhalana' kodwa uthi 'umabhalana ebhankini', ungathi u'mphathi' nje kodwa yithi 'umphathi weentengisi':*
- .....*

78. Ingaba ufna ukusebenza ngaphezulu, ngaphantsi okanye isixa seeyure ezilinganayo nezo ukuzisebenza ngaphambili?

- liyure ezingaphezulu
- liyure ezingaphantsi
- Isixa esifanayo

	1 Akukho ngxaki	2	3	4	5 Kukho ingxaki enkulu
--	-----------------------	---	---	---	---------------------------------

79. Ingaba kuyingxaki engakanani ukuba wenze izinto ziqhube njengoko zifunwa emsebenzini?

- |                       |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|

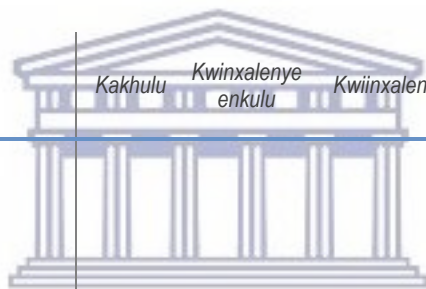
80. Ingaba kuyingxaki kangakanani ukufikelela emsebenzini?

*Umz. ukufikelela kwisakhiwo, iofisi okanye ithoyilethi yakho*

- |                       |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|

81. Ingaba unazo izixhobo zokukuncedisa ongasisebenzisa xa usemsebenzini ?

*umz., izixhobo ezincedisayo zekhomyutha, iitafle ezilungelelaniswayo okanye izixhasi-ngalo /izandleokanye izixhasi-milenze.*



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Kakhulu      Kwinxalenye enkulu      Kwiinxalenye      Kancinane      Andiyidingi tu kwaphela      Andinasidingo sinjalo

- |                       |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|

Le mibuzo mibini ilandelayo ibhekisa kumsebenzi wakho kwangoku. Kwintetha nganye kwezi zilandelayo, nceda uphawule ukuba ingaba uyavuma kakhulu, uyavuma, awuvumi okanye awuvumi kakhulu.

	Uvuma kakhulu	Uyavuma	Awuvumi	Awuvumi kakhulu
--	---------------	---------	---------	-----------------

82. Ndifumana ukwamkeleka okundifaneleyo emsebenzi wam.

- |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|

83. Xa ndiqwalasela zonke iinzame zam kunye

- |                       |                       |                       |                       |                       |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|

nendikufezekisileyo, umvuzo  
wam awanelanga.

→ *Nceda uye kumbuzo wama-*  
*87*

84. Ingaba uthanda ukuba nomsebenzi ohlawulwayo?


- Ewe
- Hayi

85. Ingaba uziva ukulungele ukwenza umsebenzi ohlawulayo?

- Ewe, iyure e-1 ukuya kwezi-11 ngeveki
- Ewe, iiyure ezi-12 ukuya kwezingama-20 ngeveki
- Ewe, iiyure ezingaphezu kwama-20 ngeveki
- Hayi, andifuni tu kwaphela

86. Zithini izizathu ezibangela ukuba ube awusebenzi ngoku?

*Krwela oko kuhambelanayo*

- Imeko zempilo okanye zokukhubazeka
- Ndisafuunda okanye ndisaqeqeshwa
- Uxanduva losapho
- Andiwufumani umsebenzi ondifaneleyo
- Andiyazi ukuba ndiwufune njani okanye ndiwukhangele njani umsebenzi
- Andinazidingo zezimali
- Abazali okanye iqabane alifuni ukuba ndisebenze
- linkonzo zothutho ezinqongopheleyo
- Ukungafikeleli kwiindawo ezinganengqesho (umz., ukungena kwizakhiwo, iofisi okanye ithoyilethi yakho)
- Ukunqongophala kwezixhobo ezincedisayo
- Ukoyika ukulahlekelwa sisibonelelo sokukhubazeka (umz., iintlawulo zepenshini, ikhava yeinshorensi yempilo)
- Andifuni kusebenza
- Okunye, nceda ucacise:  .....

## limeko zendalo ezisingqongileyo

Kubomi bethu bemihla ngemihla, siba kwimpembelelo zangaphandle zezinto ezahlukeneyo okanye iimeko zendalo ezisingqongileyo. Ezi zinto zingenza ubomi bemihla ngemihla bube lula okanye bube nzima. Cinga ngezi veki zine zidlulileyo, nceda uthekelelele ukuba ingaba ezi meko zendalo ezisingqongileyo zinefuthe elingakanani kwintatho-nxaxheba yakho phakathi koluntu.


	Ayingeni	Ayinafuthe	Yenza ubomi bam bube nzinyana	Yenza ubomi bam buze nzima
87. <b>Ukungafikeleli okanye ukungakwazi ukufikelela kwiindawo zoluntu</b> <i>Umz., ukungafikeleleki kwezakhiwo zoluntu, iipaki</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
88. <b>Ukungafikeleli okanye ukungakwazi ukufikelela kumakhaya abahlobo nezalamane</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
89. <b>Ilimo zezulu ezingentlanga</b> <i>Umz., imozulu, ixesha lonyaka, amaqondo obushushu, ulophu</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
90. <b>Izimvo zoluntu ezingentlanga ngakubantu abakhubazekileyo</b> <i>umz., ukucalula, ityheneba, ukungahoyi</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
91. <b>Izimvo ezingentlanga zosapho nezalamane malunga nokukhubazeka kwakho</b> <i>umz., ukucalula, ukunqongophala kwenkxaso, imeko yokukhuselo olugqithisileyo</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
92. <b>Izimvo ezingentlanga zabahlobo bakho malunga nokukhubazeka kwakho</b> <i>umz., ukucalula, ukunqongophala kwenkxaso, imeko yokukhuselo olugqithisileyo</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
93. <b>Izimvo ezingentlanga zabamelwane, abantu obaziyo noogxa bakho emsebenzini malunga nokukhubazeka kwakho</b> <i>umz., ukucalula, ukunqongophala kwenkxaso, imeko yokukhuselo olugqithisileyo</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
94. <b>Ukunqongophala okanye ukungabikho kobungcaphephe kwezancedisi ezizakwenza ukwazi ukuhambahamba imiganyana emifutshane</b> <i>Umz. Izitepusi ezihamba ngombane, ikheji, izancedisi-kuhamba okanye isitulo esinamavili</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
95. <b>Ukunqongophala okanye ukungafaneleki kwezinto zothutho kwimigama emide</b>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	<i>Umz. ukunqongophala kweemoto ezifanelekileyo okanye kunzima ukusebenzisa izithuthi zikawonke wonke</i>				
<b>96.</b>	<b>Ukunqongophala okanye ukunganeliseki ngoncedo lwamanesi kunye neenkonzozo zenkxaso</b> <i>Umz. Uncedo lwezempilo ekhaya okanye ukuncediswa wena buqu.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>97.</b>	<b>Ukunqongophala okanye ukungoneliiswa ngamayeza kunye nezixhobo nezibonelelo zonyango</b> <i>Umz., umbhobho womchamo, izibulali-ntsholongwane, izixhasi, imiqamelelo</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>98.</b>	<b>Iimeko zeengxaki zezimali</b> <i>Umz., ukunqongophala kwemali</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>99.</b>	<b>Ukunqongophala okanye ukungoneli kwezixhobo zokunxibelelwano</b> <i>Umz., ukunqongophala okanye ukungoneli kwezixhobo zokubhala, iikhompyutha, ifowuni, iimawusi</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>100.</b>	<b>Ukunqongophala okanye ukungoneli kweenkonzo zikarhulumente</b> <i>umz., impepha ezixhasa ukukhubazeka okanye ezinye izibonelelo</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Inkonzo zempilo**

**101. Ngobani ababoneleli ngonophelo lwempilo othe wabandwendwela okanye ngoobani abathe bakundwendwela ekhaya kwezi nyanga zilishumi elinambini zidlulileyo?**

*Krwela konke okungenayo*

- Ugqirha osekuhlaleni/ugqirha okwinkonzo zempilo ekuhlaleni/ugqirha wokukubuyisela kwisimo sakho/ugqirha oyingcaphephe kumonzakalo womnqonqo
- Enye ingcaphephe yogqirha *umz., ugqirha wotyando, ugqirha wabafazi, ugqirha wengqondo, ugqirha wamehlo*
- Umongikazi okanye umbelekisi
- Ugqirha wamazinyo
- Umeluli wamathambo
- Ingcali yamathambo
- Umncedisi wezandla nokwenza umsebenzi
- Igcisa lokusebenza ngengqondo
- Umntu onyanga ngezinye iindlela zonyanga *umz., umntu osebenzisa amayeza esintu, umntu onyanga ngeenaliti*
- Usomachiza
- Unompilo emakhayeni
- Abanye, nceda ucacise:  .....

- Andikhange ndindwendwele nawuphi na umboneleli ngeenkonzonakekelo lwempilo kwezi nyanga zilishumi elinambini zidlulileyo

102. Kwezi nyanga zilishumi linambini zidlulileyo, zingaphi izihlandlo oye wangeniswa njengesigulane esibhedlele, izakhiwo zovuselelo okanye ezinye izakhiwo zonakekelo kangangenyanga ubuncinane?

*..... (izihlandlo)*

Undwendwelo lwakho kumboneleli ngonakekelo lwempilo, ungazithelekela njani ezi meko zilandelayo:	<i>Lungaluhlanga kodwa lungelubi</i>				
	<i>Lunge kakhulu</i>	<i>Lungile</i>	<i>Lubi</i>	<i>Lubi kakhulu</i>	
103 ...amava akho ngokuphathwa ngentlonipho?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
104 ...ababoneleli ngonakekelo lwempilo bazichaze njani izinto kuwe?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
105 ...amava akho ekwenziweni kwezigqibo ngonyango lwakho?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

106 Kwezi nyanga zilishumi elinambini zidlulileyo, ukhe wadinga unakekelo lwempilo kodwa alufumana?

- Hayi
- Ewe. Zeziphi izizathu ezicacusa kutheni ungakwazanga ukufumana unakekelo lwempilo oludingayo?

*Krwela konke oko kuhambelanayo*

- Andikhange ndikwazi ukumelana neendleko zotyelo
- Bekungekho zinkonzo
- Akukho zithuthi zikhoyo
- Andikhange ndikwazi ukumelana neendleko zezothutho
- Ndandiphethwe kakubi kwixa elidlulileyo
- Bendingakwazi ukuphuma emsebenzini okanye bekukho ezinye izinto ezindibambileyo
- Amachiza okanye izixhobo zomboneleli ngonakekelo lwempilo bezinganelanga
- Izakhono zomboneleli ngonakekelo lwempilo bezinganelanga
- Andazanga ukuba mandiyephi
- Uzamile kodwa walelwa unakekelo lwempilo
- Ucinge ukuba awuguli
- Okunye, nceda ucacise: *.....*

Undwendwelo lwakho kumboneleli ngonakekelo lwempilo, ungazithelekela njani ezi meko zilandelayo:	<i>Andanelisekanga tu kwaphela</i>				
	<i>Ndanelisele kakhulu</i>	<i>Ndanelisekile</i>	<i>Ndaneliseke ndinganelisekanga</i>	<i>Andanelisekanga</i>	<i>Andanelisekanga tu kwaphela</i>
107 Ngokuphangaleleyo, ingaba waneliseke kangakanani ngeenkonzonakekelo lwempilo?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



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zempilo eziqhutywa  
kummandla wakho?



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## limeko zobuqo

Le mibuzo ilandelayo ingokuba usibona njani isiqu sakho.

	1 <i>Andizithembanga tu</i>	2	3	4	5 <i>Ndizithembe kakhulu</i>
108 . Uzithembe kangakanani ukuba ube ungafumana iindlela zokufumana loo nto uyifumana ukuba kukho umntu okuphikisayo?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
109 . Uzithembe kangakanani ukuba ungajongana ngqo neziganeko ezingalindelekanga?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
110 . Uzithembe kangakanani ukuba ube ungagcina uqhagamshelwano nabantu ababalulekileyo kuwe?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
111 . Uzithembe kangakanani ukuba ungazigcina ukwimpilo entle?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
112 . Ingaba ucinga ukuba ukuphila nomonzakalo komnqonqo kukwenze wangumntu owomeleleyo?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
113 . Ingaba unenkxalabo yokuba kuza kwenzeka ntoni kwixa elizayo?  <i>Umz., cinga ngokungakwazi ukuzinakekela, okanye ukuba ngumthwalo kwabanye kwixesha elizayo</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
114 . Ingaba ucinga ukuba uza kukwazi ukufezekisa amaphupha, amathemba, neminqweno yakho?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
115 . Ingaba ukhe wenze izigqibo ezinkulu ngobomi bakho?  <i>Umz. ukugqiba apho uza kuhlala khona okanye ingaba uza kuhlala nabani, uza kuyichitha njani imali yakho</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

116 Ingaba uziva ubandakanyeka xa uphakathi kwabanye abantu?

117 Ingaba kwezi nyanga zilishumi elinambini zidlulileyo, kukhe wehlelwa sisiganeko esibi esikhulu ebomini bakho?

Umz. imeko exhalabisayo yempilo okanye ingozi, ukuxabana nabanye abantu, ukuqhawula umtshato okanye ukuswelekelwa ngomntu omthandayo

Hayi

Ewe, nceda ucacise:  .....

**Ikhwaliti yobomi nempilo ngokubanzi**

Le mibuzo ilandelayo ingokuba uyithelekelela njani ikhwaliti yobomi bakho kwezi ntsuku zilishumi elinesine zidlulileyo. Nceda ucinge ngamanqanaba, amathemba, iziyolo neenkxalabo.

<u>Kwezi ntsuku zilishumi elinesine zidlulileyo ...</u>	<i>Iphantsi kakhulu</i>	<i>Iphantsi</i>	<i>Ayikho phantsi kodwa ayikho phezulu</i>	<i>Iphezulu</i>	<i>Iphezulu kakhulu</i>
118. Ingaba ungayithelekelela kowuphi umyinge ikhwaliti yobomi bakho?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
119. Ingaba waneliseke kangakanani ngempilo yakho?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
120. Ingaba waneliseke kangakanani ngokwenza imisetyenzana yemihla ngemihla?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
121. Ingaba waneliseke kangakanani ngesiqu sakho?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
122. Ingaba waneliseke kangakanani ngobudlelwane bakho nabanye abantu?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
123. Ingaba waneliseke kangakanani ngeemeko zakho zokuphila?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

124. Ngokuphangaleleyo, ungathi impilo yakho:

- Ibalasele
- Ilunge kakhulu
- Ilungile
- Iphakathi nje
- Ihluphekile

125. Xa uthelekisa sithuba sonyaka odlulileyo, ingaba ungayithelekela njani impilo yakho ngokuphangaleleyo ngoku?

- Ingcono kakhulu
- Ingconwanyana
- Iyafana
- Iyehla
- Yehle kakhulu



**Enkosi ngokuthabatha inxaxheba  
kuvavanyo-zimvo lwe-InSCI!**

## Appendix 11: English Consent Form



### UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa  
Tel: +27 71 614 2879  
E-mail: 29272828@myuwc.ac.za

#### CONSENT FORM

**Title of Research Project: Survival and secondary medical conditions of persons with traumatic spinal cord injury in South Africa**

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

Participant's name.....

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: Dr Conran Joseph**

**Telephone: (021) 959 2542/ 3662**

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## Appendix 12: Afrikaans Consent Form



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#### TOESTEMMINGSVORM

**Navorsingsprojek Titel: Oorlewing en sekondêre mediese toestande van persone met traumatiese spinaalkoordsbeserings in Suid Afrika**

Die studie was aan my verduidelik in 'n taal wat ek verstaan. My vrae oor die studie is beantwoord. Ek weet wat my deelname behels en neem deel uit eie keuse en vrye wil. Ek aanvaar dat my identiteit nie bekend gemaak sal word nie. Ek mag ter enigertyd van die studie onttrek en dit sal my geensins negatief beïnvloed nie.

**Naam van deelnemer .....**

**Handtekening .....**

**Datum.....**

Sou u enige vrae of klagtes oor die studie hê, voel vry om die studietoënskrywer te raadpleeg.

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## Appendix 13: IsiXhosa Consent Form



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#### IPHEPHA LEMVUME

**Isihloko sophando: Ukuphila nobumi bempilo yabantu abahlaselwe kukonzakala  
komnqonqo eMzantsi Afrika**

Olu phando lucacisiwe kum ngolwimi endilivayo nendilugqondayo. Imibuzo yam ngoluphando iphendulekile. Ndiyaqonda ukuba andinyanzelekanga ndithathe inxaxheba kolu phando, Ndiyaqonda ukuba inkcukacha zam azizokuxelelwa mntu. Ndiyaqonda ukuba ndinelungelo lokuphuma kolu phando xa ndifuna ngaphandle koloyikko lwezohlwayo okanye ukuphuncukana nenzuzo.

Igama.....

Isityikityo.....

Umhla.....

Ukuba unemibuzo ngolu phando okanye ufuna ukuxela iingxaki othe wabanazo, nceda qhagamshelana noququzela olu phando:

**Umququzeleli wopho: Gqirha Conran Joseph**

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## Appendix 14: Editorial Certificate

05 November 2018

To whom it may concern

Dear Sir/Madam

### RE: Editorial Certificate

This letter serves to prove that the thesis listed below was language edited for proper English, grammar, punctuation, spelling, as well as overall layout and style by myself, publisher/proprietor of Aquarian Publications, a native English speaking editor.

#### Thesis title

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AFRICA

#### Author

Vuyolwethu Madasa

There seemed to be a reluctance on the part of the author to respond to certain queries, specifically related to figures in tables and related text; therefore, the edited thesis was delivered incomplete. However, the research content, or the author's intentions, were not altered in any way during the editing process, and the author has the authority to accept or reject my suggestions and changes.

Should you have any questions or concerns about this edited document, I can be contacted at the listed telephone and fax numbers or e-mail addresses.

Yours truly



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