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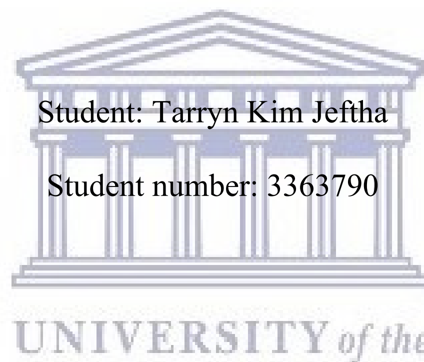
Faculty of Community and Health Sciences

Health status and functioning after traumatic spinal cord injury in South Africa: Comparison between a private and a public health care funded cohort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A thesis submitted in fulfilment of the requirements for the degree of
Master of Science in the Department of Physiotherapy,
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KEYWORDS

Spinal cord injury

Traumatic spinal cord injury

Disability

International Classification of Functioning, Disability and Health

Impairment

Activity limitation

Participation

Private healthcare sector

Public healthcare sector

Quality of care

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ABSTRACT

Introduction: A spinal cord injury is the damage to the spinal cord that alters functional independence. Two different systems of care for the management of health conditions are available in private and public care in South Africa. A better understanding of health and functioning of individuals in the two systems is crucial to help address inequality between the two systems. The aim of the study was to describe the health status and functioning of persons with traumatic spinal cord injury (TSCI) in the Western Cape province who received public-funded care compared with those in the Gauteng province who received private care. **Methodology:** The study entailed a cross-section comparison between a government-funded cohort in the Western Cape and a private cohort in Gauteng, two of the provinces of South Africa. Self-administered questionnaires and standardised outcome measures were used to collect the data and to ensure validity and reliability. Data were captured on Excel and then transferred to SPSS (Statistical Package for Social Sciences) for analysis. Ethical clearance to conduct the study was obtained from the Biomedical Research Ethics Committee of the University of the Western Cape. **Results:** The private sectors cohort has 41 participants with an average age of 38.3, whereas the public sector has 97 participants with an average age of 44. Significant differences were found between the cohorts, with the private cohort being more independent than the public cohort in the execution of grooming (P=0.049). The private cohort has a higher proportion of "no problem" with participation in carrying out daily routine (p=0.000) compared to the public cohort. The private cohort experienced far fewer responses than the public cohort in the "No problem" category in the secondary complications. There was a significant association between cohorts with respect to: missing or insufficient accessibility to public places (p=0.000), lack of or insufficient adapted assistive technology for moving around short and long distances (p=0.000), lack of or

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insufficient nursing care and support services, medical aids, state services and problematic financial situation (p=0.000). **Conclusion:** The two cohorts differed based on some injury characteristics, while the public-funded sector experienced more activity limitations, participation restrictions, secondary complications and environmental challenges. This information could be used to strengthen systems of care for people living with TSCI.

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DEDICATION

I dedicate this thesis to my mother, Karin Jeftha, my father, Gerald Jeftha, my brother, Alphonzo Jeftha, and my niece, Kaia Jeftha, who, with their love and belief in me have always created an enabling environment that helped me to optimise my potential. They have been extremely supportive in my endeavour to complete my thesis successfully. I love, honour and appreciate you. What I have achieved in life you get credit for.

"Commit to the Lord whatever you do, and He will establish your plans"-Proverbs 16:3

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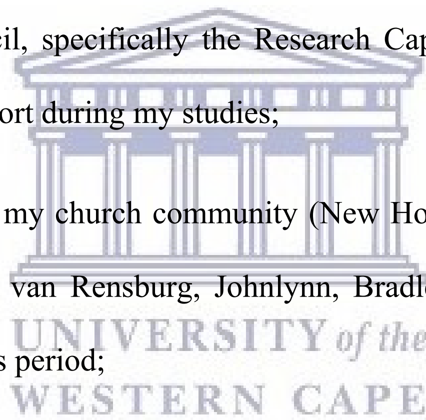

The Physiotherapy staff at the University of the Western Cape for their encouragement – a special word of thanks!

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http://etd.uwc.ac.za/

CONTENTS

KEYWORDS........2
ABSTRACT........3
DEDICATION........5
ACKNOWLEDGEMENTS........6
LIST OF APPENDICES........10
LIST OF TABLES........10
ABBREVIATIONS........11
CHAPTER 1: BACKGROUND TO THE STUDY........12
1.1 INTRODUCTION........12
1.2 BACKGROUND TO THE STUDY........12
1.3 PROBLEM STATEMENT........15
1.4 RESEARCH QUESTION........16
1.5 AIM OF THE STUDY........16
1.6 OBJECTIVES OF THE STUDY........16
1.7 DEFINITIONS OF KEY TERMS........17
1.8 OUTLINE OF CHAPTERS........17
CHAPTER 2: LITERATURE REVIEW........19
2.1 INTRODUCTION........19
2.2 EPIDEMIOLOGY........19
2.3 ACTIVITY LIMITATIONS AFTER TSCI........21
2.3.1 Financial factors relating to activity limitation........21
2.4 PARTICIPATION AFTER TSCI........22
2.5 SECONDARY COMPLICATIONS........25
2.5.1 Pressure ulcers........26
2.5.2 Urinary tract infections and neurogenic bowel and bowel dysfunction........26
2.5.3 Respiratory and heart conditions........26
2.5.4 Contractures........27
2.5.5 Psychological disorders and pain syndromes........27
2.5.6 Spasticity........27
2.5.7 Osteoporosis and bone fractures........27
2.6 THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF)........28

UNIVERSITY of the
WESTERN CAPE

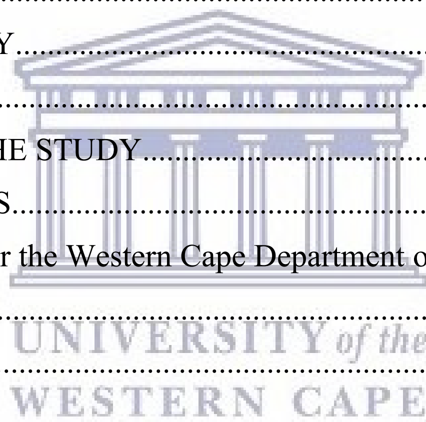
http://etd.uwc.ac.za/

2.7 ENVIRONMENTAL FACTORS....31
2.8 REHABILITATION PROCESS AND THE DIFFERENT SYSTEMS OF CARE......31
2.9 SHORTCOMINGS OF GOVERNMENT-FUNDED MEDICAL PRACTICES IN THE DEVELOPING WORLD....35
2.9.1 Poor evacuation protocols and inadequate pre-hospitalisation care....35
2.9.2 Inadequate access to advanced radiological imaging techniques....35
2.9.3 Access to specialised spinal cord injury wards and centres....36
2.9.4 Spinal cord injury rehabilitation services in the developing world....37
2.10 CONCLUSION....38
CHAPTER 3: METHODOLOGY....39
3.1 INTRODUCTION....39
3.2 RESEARCH DESIGN....39
3.3 RESEARCH SETTINGS....39
3.4 STUDY SAMPLING AND POPULATION....40
3.5 INCLUSION CRITERIA....40
3.6 EXCLUSION CRITERIA....41
3.7 RESEARCH INSTRUMENT, VALIDITY AND RELIABILITY....41
3.8 PROCEDURE....43
3.9 DATA ANALYSIS....44
3.10 ETHICS....45
3.11 CONCLUSION....45
CHAPTER 4: RESULTS....47
4.1 INTRODUCTION....47
4.2 OBJECTIVE 1: EPIDEMIOLOGY....47
4.3 OBJECTIVE 2: ACTIVITY LIMITATIONS....49
4.4 OBJECTIVE 3: PARTICIPATION RESTRICTION....52
4.5 OBJECTIVE 4: SECONDARY COMPLICATIONS....57
4.6 OBJECTIVE 5: ENVIRONMENTAL RESTRICTIONS AND QUALITY OF LIFE..59
CHAPTER 5: DISCUSSION OF THE RESULTS....63
5.1 INTRODUCTION....63
5.2 EPIDEMIOLOGY....63
5.2.1 Gender, age and marital status....63
5.2.2 Aetiology, injury duration level and completeness of injury....64
5.2.3 Years of educational training and perceived financial status....65
5.3 ACTIVITY LIMITATIONS....65

UNIVERSITY of the
WESTERN CAPE

http://etd.uwc.ac.za/

5.4 PARTICIPATION RESTRICTIONS....66
5.4.1 Transport....66
5.4.2 Physical factors....67
5.4.3 Social and emotional factors....67
5.4.4 Vocational factors....68
5.5 SECONDARY COMPLICATIONS....70
5.6 ENVIRONMENTAL FACTORS....71
5.6.1 Physical barriers....71
5.6.2 Attitudes....71
5.6.3 Services and financial barriers....72
5.7 QUALITY OF LIFE....72
5.8 SUMMARY OF THE CHAPTER....72
CHAPTER 6: SUMMARY OF STUDY....74
6.1 INTRODUCTION....74
6.2 SUMMARY OF STUDY....74
6.3 LIMITATIONS....75
6.4 SIGNIFICANCE OF THE STUDY....76
6.5 RECOMMENDATIONS....76
6.5.1 Recommendation for the Western Cape Department of Health....77
CHAPTER 7: REFERENCES....78
APPENDICES....87



http://etd.uwc.ac.za/

LIST OF APPENDICES

Appendix 1: Permission to conduct the study from the Senate Research Grants

Appendix 2: Participant information sheet in English

Appendix 3: Participant information sheet in Afrikaans

Appendix 4: Participant information sheet in IsiXhosa

Appendix 5: Participant consent form in English

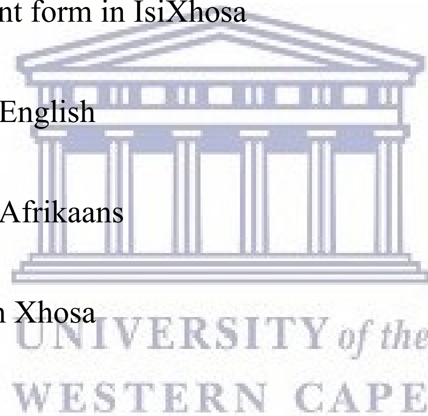
Appendix 6: Participant consent for in Afrikaans

Appendix 7: Participant consent form in IsiXhosa

Appendix 8: Questionnaire in English

Appendix 9: Questionnaire in Afrikaans

Appendix 10: Questionnaire in Xhosa


UNIVERSITY of the
WESTERN CAPE

LIST OF FIGURES

Figure 2.1: An illustration of the interaction of components of the ICF.

LIST OF TABLES

Table 4.1: Epidemiological characteristics

Table 4.2: Activity limitations

Table 4.3: Participation restriction

http://etd.uwc.ac.za/

Table 4.4: Secondary complications

Table 4.5: Environmental restrictions and quality of life

ABBREVIATIONS

ICF	International Classification of Functioning, Disability and Health
MDS	Model Disability Questionnaire
MVAs	Motor vehicle accidents
TSCI:	Traumatic Spinal Cord Injury
SCI:	Spinal Cord Injury.
WHO:	World Health Organization.

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CHAPTER 1: BACKGROUND TO THE STUDY

1.1 INTRODUCTION

This chapter commences with a background to the research field of spinal cord injuries. It contextualises traumatic spinal cord injuries in the public healthcare sector of the Western Cape and the private healthcare sector in Gauteng. It further explores the functioning of traumatic spinal cord injury (TSCI) patients as a result of their financial state and the system of care by which they are being treated. This chapter also presents the problem statement, aims, objectives and significance of the study. The chapter concludes with the definitions of key terms used in the study and an outline of the chapters.

1.2 BACKGROUND TO THE STUDY

Prior to World War II, individuals who had sustained spinal cord injuries (SCI) had an expected survival of weeks only, since no comprehensive and specialised services, including rehabilitation, were available (Ullrich, Spungen, Atkinson, Bombardier, Chen & Erosa, 2012). The advancement in antibiotics, emergency medicine, acute medical care and the availability of rehabilitation services improved the survival rate of such persons (Ullrich, Spungen, Atkinson, Bombardier, Chen & Erosa, 2012; Rathore, 2010; Joseph, 2016). As a result of these advancements, persons who have sustained spinal cord injuries are now able to have a comprehensive restoration of their functional, social, emotional and recreational wellbeing (Ullrich, Spungen, Atkinson, Bombardier, Chen & Erosa, 2012).

An SCI is defined as the damage to the spinal cord that alters its function, either temporarily or permanently (Krause & Saunders, 2011). These changes translate into loss of muscle function, sensation, or autonomic function in parts of the body innervated by the spinal cord

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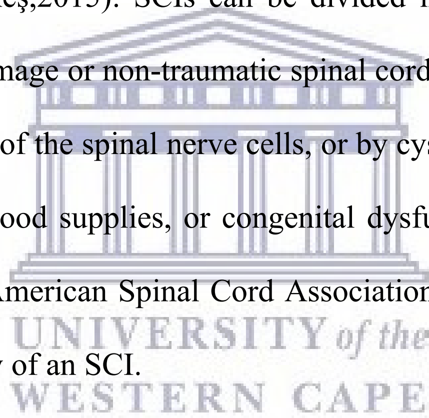
below the level of the lesion (Krause & Saunders, 2011). Rathore (2010) points out that 5 000 years ago, SCI was labelled as an ailment not to be treated. Unfortunately, in the undeveloped countries not much has changed (Rathore, 2010). In the developed world many large-scale studies have been conducted in the form of epidemiologic questionnaires, multicentre research on interventions in acute SCI, reports of complications from acute and chronic SCI, results of rehabilitation interventions and functional outcomes but these studies have excluded the developing world (Rathore, 2010).

An SCI causes a decrease in mobility, functional independence and challenges with employment and socialisation (Arango-Lasprilla, Starkweather, Nicholls, & Wilk, 2009; Nas, Yazmalar, Sah, Aydin, & Öneş,2015). SCIs can be divided into TSCI, where an external force is responsible for the damage or non-traumatic spinal cord injury, where the injuries are typically caused by infections of the spinal nerve cells, or by cysts or tumours pressing on the spinal cord, interruption of blood supplies, or congenital dysfunction (Rahimi-Movaghar et al., 2013). The standardised American Spinal Cord Association Impairment Scale is used to diagnose the level and severity of an SCI.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There are two different systems of care for the management of health conditions available in South Africa. The private sector provides specialised care with its units fully staffed with an entire multidisciplinary team ranging from orthopaedic surgeons to counsellors, whereas the public sector has a more general approach to managing this health condition due to a lack of resources and capacity, compared to the public sector. The private sector's specialised approach has a formal chain of care, starting with evidence-based pre-hospitalisation care, acute care, rehabilitation and then outpatient rehabilitation (Joseph, 2016).

In the public healthcare sector of the Western Cape there are only two appropriate units for SCI, one for acute cases and the other for rehabilitation (Joseph, 2016). As a result of

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constraints in terms of resources in the public healthcare sector, patients are only seen on a referral basis, causing quality care to be delayed. Patients are seen based on priority at two available healthcare facilities (Joseph, 2016). The private specialised system of care allows for individuals problems to be addressed along the disease continuum. In the public sector, patients are discharged without any follow-up appointments, resulting in their being lost in the system and developing secondary complications that could have otherwise prevented (Joseph, 2016).

It is imperative, therefore, to get a snapshot of the functioning of patients in the two systems in order to gain an understanding of how the different systems affect the health status and functioning of persons with TSCI. This information can be used to address the inequality in the healthcare sectors. The National Core Standards for Health Establishment in South Africa ensures that the quality of government funded healthcare services received is of the same quality in each province (Whittaker, Shaw, Spieker & Linegar, 2011). In this study two different provinces were compared: one in the north and one in the south of South Africa in order to learn more about health systems. Furthermore, regardless of the differences in demographic and environmental factors, the quality of care and standard of care in both the private and public sectors remains uniform, theoretically speaking, in terms of using evidence-based management (Whittaker et al., 2011). However, availability and access typically differ between systems.

The operative framework used to describe the health status and functioning is the International Classification Framework of Functioning, Disability and Health. It structures information in a meaningful, interrelated and accessible way, aiding in better understanding the condition (WHO, 2013). It has two parts: Part 1 deals with functioning and disability (body components and activities and participation), whereas Part 2 deals with contextual

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factors (environmental and personal factors) (WHO, 2013). A lower socioeconomic status and the presence of co-morbid medical complications prior to sustaining a spinal cord injury will lower a person's ability to optimise functional abilities post injury (Ullrich, Spungen, Atkinson, Bombardier, Chen & Erosa, 2012). Financial support is also a favourable condition for optimising recovery (Ullrich, Spungen, Atkinson, Bombardier, Chen & Erosa, 2012).

1.3 PROBLEM STATEMENT

Healthy ageing post TSCI depends on the absence of secondary complications, optimal levels of activity and participation, and a well-functioning healthcare system that responds to threats in a time-sensitive manner (Chamberlain, Meier, Mader, Von Groote, & Brinkhof, 2015; Savic et al., 2017). There is, however, no consistent chain of healthcare in the public healthcare system available for TSCI in South Africa. It is imperative to gain a better understanding of the health care and functioning of persons in the two systems, i.e. private- versus public-funded. This information can be used to address inequality and, in turn, it could result in positive adaptations to be made in the health care sectors.

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Regardless of the healthcare plan, very little is known about the activity limitations and participation restrictions of TSCI in private hospital rehabilitated patients compared to public hospital rehabilitated patients in Gauteng and the Western Cape, South Africa. These two provinces were chosen due to similar approaches in managing persons with TSCI and because of a similarity in socio-demographic profiles and environmental context, i.e. urban and peri-urban areas.

1.4 RESEARCH QUESTION

The research question for this study was formulated as follows:

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What is the health status and functioning of persons with TSCI in the Western Cape province who received public-funded care compared with those in the Gauteng province who received private care?

1.5 AIM OF THE STUDY

The aim of the study was to describe, and compare the health status and functioning of persons with TSCI in the Western Cape province who received public-funded care and those in the Gauteng province who received private care.

1.6 OBJECTIVES OF THE STUDY

The objectives of the study were the following:

1. To describe the epidemiological characteristics of two cross-sectional cohorts, a private cohort and a public cohort with TSCI, according to the International Basic Core Data Set.

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2. To determine activity limitations and participation restrictions of persons with TSCI living in the Western Cape (public cohort) compared with Gauteng (private cohort), South Africa.

3. To determine secondary health problems of persons with TSCI living in the Western Cape (public cohort) and Gauteng (private cohort), South Africa.

4. To determine environmental factors impacting functioning in persons with TSCI, comparing private- and public-funded persons.

1.7 DEFINITIONS OF KEY TERMS

Spinal cord injury: Damage to the spinal cord that alters its function, either temporarily or permanently (Krause & Saunders, 2011).

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Traumatic spinal cord injury: Damage to the spinal cord caused by external forces, resulting in complete or partial loss of sensation and movement, including incontinence (Øderud, 2014).

Public cohort: The healthcare system in accessible to the public, without any cost, offering only two appropriate units for SCI, i.e. one for acute cases and the other for rehabilitation (Joseph, 2016).

Private cohort: The healthcare system that has a specialised approach and a formal chain of care, starting with evidence-based pre-hospitalisation care, acute care, rehabilitation and then outpatient rehabilitation (Joseph, 2016).

ICF: It is a universal framework for allied health professionals, standardising and unifying the description of health and health-related issues (WHO, 2001).

Health status and functioning: The degree of health and ability to fulfil a task based on an objective measure (In this case the Insc questionnaire).

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Activity: A task executed by a person (WHO, 2013)

Activity limitation: Complications that a person has with executing a task (WHO, 2013)

Disability: Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions (WHO, 2013).

Impairment: The loss or malfunctioning of a physiological or anatomical structure of the body (Rathore, 2010)

Participation: The degree of a person's involvement in life situations in relation to their impairment, activities, health condition and contextual factors (WHO, 2013)

Participation restrictions: Complications related to the execution of life situations (WHO, 2013)

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Rehabilitation: The action of restoring something that has been damaged or injured to its former condition or closest to it, through therapy and training

1.8 OUTLINE OF CHAPTERS

Chapter 1 presents the background of the study by introducing important concepts. The broad aim of the study is thus condensed. The chapter also provides a backdrop for the study, the motivation and importance of the study and the objectives, as well as the definition of terms.

Chapter 2 summarises a narrative review of the pertinent literature to help the reader understand the importance of the implementation of the study. It further highlights the gap of knowledge.

Chapter 3 explores the methodology employed to answer the study objectives. The research design, study sample, development of questionnaires and data analysis are discussed.

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Chapter 4 contains the results of the quantitative data that were used in an attempt to answer the objectives.

Chapter 5 discusses the pertinent results relating to the aims and objectives with reference to published literature. Mention is made of how the results affect the private and public cohorts.

Chapter 6 provides the conclusion, based on the results. Recommendations are made for both the private and the public sector, based on the findings of the study, as well as on research that emerged from the literature review. The limitations of the study are also mentioned.

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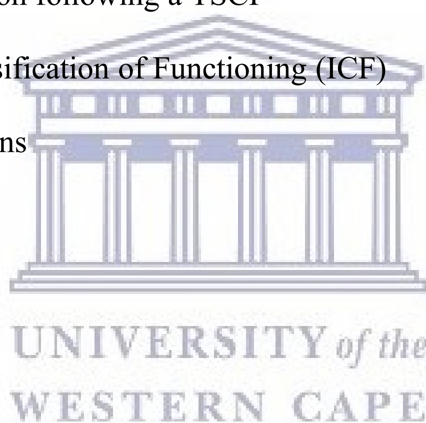
CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

In the previous chapter the background, problem, purpose, objectives, research question and aim were described. In this chapter these aspects are discussed in greater depth.

The following topics are explored in this chapter:

- Epidemiology of TSCI patients in South Africa
- Activity limitations following a TSCI
- Community participation following a TSCI
- The International Classification of Functioning (ICF)
- Secondary complications
- Environmental factors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2.2 EPIDEMIOLOGY

Epidemiology is the study of the distribution, incidence and potential control of diseases and other factors relating to health (WHO, 2013). In 2014, Øderud indicated that 5.8 million people die globally each year from injuries and that traumatic injuries kill more people than HIV and AIDS and malaria combined, and road traffic accidents account for about a quarter of deaths from injuries (Øderud, 2014). More than 90% of deaths that result from injury occur in low- and middle-income countries and mortality rates from injuries are higher for people from poorer economic backgrounds than those with a higher income (Øderud, 2014). The occurrence of traumatic spinal cord injuries in South Africa is one of the highest in the world (Joseph, 2016). In South Africa specifically, gunshot injuries, motor vehicle injuries (MVAs), stab wounds and falls from heights are the most common means by which such

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TSCI are sustained (Hart & Williams, 1994; Øderud, 2014). Figures from South Africa indicate a high incidence of SCI from violence (56%), particularly gunshot injuries (36%) and stab wounds (20%) (Øderud, 2014; Moodley & Pillay, 2013), while MVAs in South Africa are mainly as a result of four-wheeled motor vehicles (Burns, O'Connell, 2012).

There is a need for primary preventative strategies to target younger men who are exposed to and engage in violent activities (Joseph, 2018). In South Africa the foundation for primary prevention and knowledge of the unmet needs of persons with TSCI has not yet been established (Joseph, 2016). Preventative measures targeting MVAs should be put in place and greater awareness should be created to prevent falls (Hagen, Rekand, Gilhus, & Grønning, 2012). Alcohol and substance abuse are potential risk factors for SCI, so it is imperative to offer education and create awareness on the detriment associated with the relationship between SCIs and alcohol and substance abuse (Øderud, 2014).

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The variation between different countries in terms of mechanisms of injury, age and gender distribution reflects variations in culture and way of life, as well as differences in the composition of the respective populations (Hagen, Rekand, Gilhus & Grønning, 2012). Those from low socioeconomic backgrounds have higher rates of drug and alcohol abuse, compared to those from higher socioeconomic backgrounds having a higher risk of heavy drinking after their injury (Fyffe, Botticello & Myaskoysky, 2011). Generally, traffic accidents are the primary cause of injury in developed nations, while falls are the leading cause in developing countries as a result of people's lifestyles in the different settings (Burns & O'Connell, 2012).

2.3 ACTIVITY LIMITATIONS AFTER TSCI

Trauma to the human spinal cord typically occurs out of the blue, leaving survivors with the initial ordeal of permanent or temporary deficits in health and functioning (Joseph, 2016).

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Mobility, stair climbing and transfers from the floor to the wheelchair were found to be the most prevalent activity limitation in patients following inpatient rehabilitation (Joseph, Statham, Mlezana, De Wet & Rhoda, 2013). Patients showed the greatest improvement from admission to discharge with regard to bathing the lower limbs, transfers from the wheelchair to the car and toileting (Joseph, Statham, Mlezana, De Wet & Rhoda, 2013). The highest level of independence was noted in grooming, feeding and respiration (Joseph, Statham, Mlezana, De Wet & Rhoda, 2013).

In Switzerland, six hours post SCI patients undergo surgery to prevent further compromise of the spinal cord. They are then rehabilitated in one of four specialized SCI rehabilitation centres for 5–12 months, depending on the severity and level of lesion of the injury, thus improving their ability to take part in meaningful activities post injury (Gross-Hemmi & Barzalla, 2017). Patients with paraplegia stay for an average of five to six months; patients with tetraplegia for approximately eight to ten months in the specialised SCI rehabilitation centres (Gross-Hemmi & Barzalla, 2017). This phase of acute inpatient rehabilitation promotes improved levels of activity by aiming to enable people with SCI to regain a maximum of autonomy, independence and the best possible inclusion into social, family and professional life (Gross-Hemmi & Barzalla, 2017).

2.3.1 Financial factors relating to activity limitation

It is evident in the literature that financial hardships may limit functioning and health in persons with disabilities. Living in severe and even financial difficulties is directly proportional to reduced functioning and quality of life (Siegrist, Reinhardt, Brinkhof & Fekete, 2014). Financial difficulties worsen people's burden of everyday life as they have restricted access to relevant resources and medical care, which generates feelings of relative

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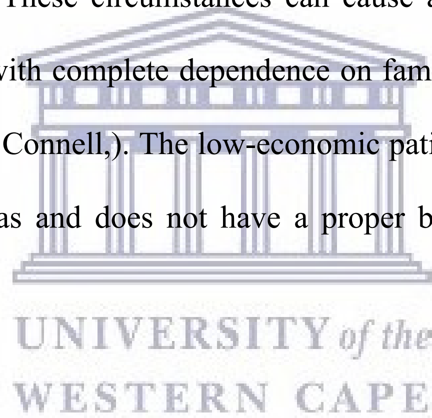
deprivation with subsequent stress reactions (Siegrist, Reinhardt, Brinkhof & Fekete, 2014). Therefore, suffering from financial hardship might reflect material disadvantage, as well as psychosocial stress (Siegrist, Reinhardt, Brinkhof & Fekete, 2014). Higher education levels are significantly associated with better psychological health and quality health (Siegrist, Reinhardt, Brinkhof & Fekete, 2014).

Persons from low-income communities depend on their physical abilities to provide for themselves and their family, often through manual labour such as farming (Burns & O'Connell, 2012). A physical disability significantly decreases one's survival advantage and this is worsened by the lack of finances and the limited accessibility of medical services (Burns & O'Connell, 2012). These circumstances can cause a person to become a virtual prisoner in his or her home, with complete dependence on family and friends, once they are discharged home (Burns & O'Connell,). The low-economic patient often has to go home to a "bush toilet" in the rural areas and does not have a proper bed or a wheelchair (Øderud, 2014).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2.4 PARTICIPATION AFTER TSCI

Participation is the involvement in life situations (WHO, 2013). The three most disrupted life habits in relation to spinal cord injury are residence maintenance, participation in occupational roles and recreational activities (Carpenter, Forwell, Jongbloed, & Backman, 2007).

SCIs cause serious functional, socioeconomic and psychological disorders (Sezer, Akker & Uğurlu, 2015). The primary role of rehabilitation is to improve function and decrease secondary complications by improving quality of life (QoL) (Seker, Akker, Uğurlu, 2015). It is imperative that prevention and early diagnosis are done to limit the occurrence of

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secondary complications (Seker, Akker, Uğurlu, 2015). As a result of low education levels and unemployment prior to the injury, persons with TSCI struggle to be reintegrated into the work environment after the injury (Øderud, 2014).

These patients are unable to purchase devices such as callipers, suited wheelchairs, urinary bags and catheters (Øderud, 2014). Also, as a result of limited accessibility of school buildings and transport expenses, youngsters that sustain an SCI tend to drop out of university (Øderud, 2014). Low-economic communities receive wheelchairs donated by charities, but these are not specifically designed for the terrain and are not suited to the individual user's body (Øderud, 2014). The ability to maintain their life habits depends on the quality of the affected person's environment and level of function (Carpenter et al., 2007). Major barriers are transportation and accessibility (between buildings).

Twenty-one to 67% of SCI patients were able to be reintegrated into the community with the help of high technology assistive devices, adapted vehicles and motorised wheelchairs; even quadriplegics were able to reintegrate (Rathore, 2010). Persons with TSCI with high levels of educational attainment are more likely to utilise customised wheelchairs and drive modified vehicles, which results in improved psychological and social outcomes post injury (Fyffe, Botticello and Myaskoysky, 2011). There are not exact percentages of community reintegration of SCI patients in the developed world, but even patients who have spinal cord lesions of the lower thoracic region struggle to reintegrate as they struggle to mobilise independently as a result of their level of spinal cord injury (Rathore, 2010). This is caused by social and mobility barriers, inconvenient transport systems, disability stigmatisation, rejection by society and insufficient vocational and avocational opportunities (Rathore, 2010). Community participation was better in participants who experienced fewer environmental barriers, and "attitudes of members of society", "accessibility of the

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environment" and "social support" influenced the participants' satisfaction with community participation (Van Der Westhuizen, Mothabeng, & Nkwenika, 2017).

Apart from the abovementioned tangible things that are advantageous for reintegration, participation is affected by personal factors, such as coping skills, rehabilitation experience, future aspirations, personal needs, psycho-emotional issues and meaningful use of time, as well as environmental factors, such as others' attitudes, social support and accessibility complications. Community participation was mainly related to three major categories of factors: personal, disability-related and environmental factors (Van Der Westhuizen, Mothabeng, & Nkwenika, 2017). Satisfaction with community participation was greater in participants who had been living with TSCI for longer, were more educated, were not black Africans, resided in suburbs and were employed (Van Der Westhuizen, Mothabeng, & Nkwenika, 2017). Again, the public cohort is affected at least one of the above-mentioned. Positivity and involvement in creative engagements improved community participation in SCI survivors (Van Der Westhuizen, Mothabeng, & Nkwenika, 2017).

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Satisfaction and community participation is significantly associated with the SCI person's race, level of education, employment, educational qualifications, years of living with SCI, level of SCI, health complications, perceived health status, functional ability and perceived environmental factors, such as physical (structural and geographic) barriers and lack of transport (Van Der Westhuizen, Mothabeng, & Nkwenika, 2017). Many of the public health cohort fall into one of the above-mentioned categories.

In developed countries, integrative measures, such as vocational rehabilitation, housing assistance and building adaptations, are started to ease the patient into community inclusion immediately after discharge from rehabilitation (Gross-Hemmi & Barzalla, 2017). Patients also have yearly follow-ups at the specialised rehabilitation centres focusing on improved

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activity levels, participation and psychological counselling in order to foster quality of life, self-reliance and self-confidence in the SCI person (Gross-Hemmi & Barzalla, 2017). In an attempt not to marginalise the financially disadvantaged group sustaining SCI, the Swiss government provides financial support to reduce the cost of health insurance premiums (Gross-Hemmi & Barzalla, 2017). Persons with SCI from a healthcare system like Sweden have been found to be higher functioning and better equipped to participate in the community (Gross-Hemmi & Barzalla, 2017).

2.5 SECONDARY COMPLICATIONS

A secondary complication develops during the course of a primary disease or condition and arises as a result of it or from an independent cause: "A spinal cord injury (SCI) creates a state of vulnerability, in that this sudden and debilitating injury most often results in chronic disability and an increased risk for secondary health complications that reframe an individual's entire life" (Fyffe, Botticello and Myaskoysky, 2011). The common secondary complications are pressure ulcers, contractures, urinary tract infections, bowel complications, and heart and respiratory conditions (Rathore, 2010). The secondary complications are explained in greater depth below.

2.5.1 Pressure ulcers

A pressure sore is a localised injury to the skin or underlying tissue usually over a bony prominence as a result of pressure and shear forces (Sezer, Akker, & Uğurlu, 2015). It is most commonly found on the ischium, trochanters, sacrum, heel, malleolus and feet (Seker, Akker, Uğurlu, 2015). This leads to further functional disability and fatal infections, and surgical

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interventions may be required (Seker, Akker, Uğurlu, 2015). Many patients develop pressure ulcers in hospital as a result of improper pressure care regimes being carried out (Burns & O'Connell, 2012; Seker, Akker, Uğurlu, 2015).

2.5.2 Urinary tract infections and neurogenic bowel and bowel dysfunction

The main reason for the occurrence of urinary tract infection in low socioeconomic communities is the inability to afford disposable catheters (Øderud, 2014). A person with SCI cannot go to the bush to attend to his bowel needs (Burns & O'Connell, 2012). As a result, chronic faecal incontinence is quite common (Burns & O'Connell, 2012). Neurogenic bowel disorder is a dysfunction in the colon as a result of lack of nervous control, where the internal and external sphincter loses its involuntary control (Seker, Akker, Uğurlu, 2015).

2.5.3 Respiratory and heart conditions

Respiratory conditions are caused by the decrease in mobility resulting in reduced vital lung capacity, respiratory muscle insufficiency, poor cough reflex, decreased lung and chest wall compliance and increased effort of breathing are common problems with SCI patients (Seker, Akker, Uğurlu, 2015).

2.5.4 Contractures

Contractures are a deformity resulting in the stiffness and constriction in connective tissues of the body; they are prevented by doing regular passive movements of the joints (Rathore, 2010).

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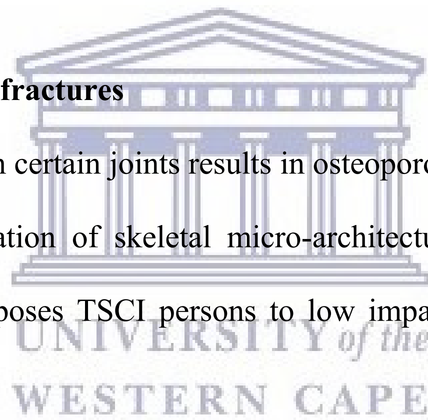
2.5.5 Psychological disorders and pain syndromes

Survivors of TSCI suffer from detrimental psychological, psychosocial and neurobehavioral issues and are at a greater risk of developing anxiety disorders, substance abuse problems, chronic pain, feelings of helplessness, poor coping skills, low self-esteem and depression (Arango-Lasprilla, Francis, Premuda, Stejskal & Kreutzer; 2009).

2.5.6 Spasticity

Spasticity is characterised by hypertonus, sustained involuntary somatic reflexes, clonus and painful muscle spasm (Sezer, Akker, 2015 and Uğurlu, 2015).

2.5.7 Osteoporosis and bone fractures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The inability to bear weight on certain joints results in osteoporosis, which is characterised by low bone mass and deterioration of skeletal micro-architecture (Sezer, Akker, 2015 and Uğurlu, 2015). It also predisposes TSCI persons to low impact fractures post SCI (Seker, Akker, Uğurlu, 2015).

2.6 THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF)

The ICF has become a universal framework for allied health professionals, since its adoption in 2001, standardising and unifying the description of health and health-related issues (Frew, Joyce, Tanner & Gray, 2008). A voice has been given clinical decision making by tacit knowledge that a therapist uses in clinical reasoning (Frew, Tanner & Gray, 2008). In the last two decades of the twentieth century, dramatic progress has been made in the conceptualisation of disability: The three levels of performance affecting disability are at

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organ level, personal level and at the societal level (Whiteneck, Meade, Dijkers, Tate, Bushnik, Forchheimer, 2004).

The ICF is a classification with specific categories. It is based on the understanding that the ability to improve functioning is a dynamic and interactive process (Frew, Tanner & Gray, 2008). Although the ICF combined the categorisation system for activities and participation, it maintained a conceptual distinction between the two dimensions. The ICF also offered a modified conceptual scheme of the links between these three aspects of disability, which for the first time explicitly showed the role of environmental factors. The complete background of an individual's life is contextualised in the ICF model (Frew, Tanner & Gray, 2008). Contextual factors include two components: environmental factors and personal factors (Frew, Tanner & Gray, 2008). The physical, social and attitudinal environment in which people live and conduct their lives is made up of the environmental factors (Frew, Tanner & Gray, 2008). These factors can either be barriers to or facilitators of the person's functioning (Frew, Tanner & Gray, 2008). Environmental factors include location, home, products, technology, service and systems (Frew, Tanner & Gray, 2008). According to the ICF model, personal factors include cultural beliefs, values and individual preferences, which may impact on other areas of the person's health condition (Frew, Tanner & Gray, 2008).

A disease or disorder is an exclusive experience for an individual and it needs to be addressed with such exclusivity (Frew, Tanner & Gray, 2008). The therapist should try to understand the condition from the patient's perspective and not only from a disease and organ level (Frew, Tanner & Gray, 2008). A health condition can impose significant limitations on a person's activities and the degree of participation that they are able to engage in, as well as personal and contextual factors that make up their life (Frew, Tanner & Gray, 2008). These personal and contextual factors can either be barriers to or facilitators of activity and

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participation (Frew, Tanner & Gray, 2008). These authors comment as follows: Factors such as their age, experiences in life, interests, relationships, community and social life, become part of the activity and participation, as represented in the ICF model (Frew, Tanner & Gray, 2008).

Poorer people have a higher risk of injuries and they suffer severely from the financial pressure resulting from injuries (Øderud, 2014). Persons with TSCI often experience secondary complications that could have been avoided by simply accessing competent healthcare services; instead, they suffer premature death as a result of secondary complications (Øderud, 2014). It is clear that a well-developed healthcare system is needed to combat the secondary complications of TSCI. Patients admitted with secondary complications also have a significantly longer hospital stay (Middleton, Dayton, Walsh, Katkowsi, Leong & Duong, 2014 et al., 2014). Furthermore, there is evidence that some socioeconomic groups are at a disproportionate risk for poorer health outcomes than others following injury (Fyffe, Botticello and Myaskoysky, 2011). An indirect association of socioeconomic situations with various health indicators is one of the most profound findings of social-epidemiological research (Siegrist, Reinhardt, Brinkhof & Fekete, 2014).
Since the ICF is linked with clinical reasoning, it emphasises the dynamic process and interactive process within each approach, instead of seeing each component as separate entities functioning in isolation (Frew, Tanner & Gray, 2008). Therapists use clinical reasoning to decide which treatment options will be more beneficial in remediating identified problems (Frew, Tanner & Gray, 2008). In engaging in this type of clinical reasoning, the therapist uses knowledge of the contextual factors involved in the therapist–patient interaction to make decisions about clinical intervention (Frew, Tanner & Gray, 2008).

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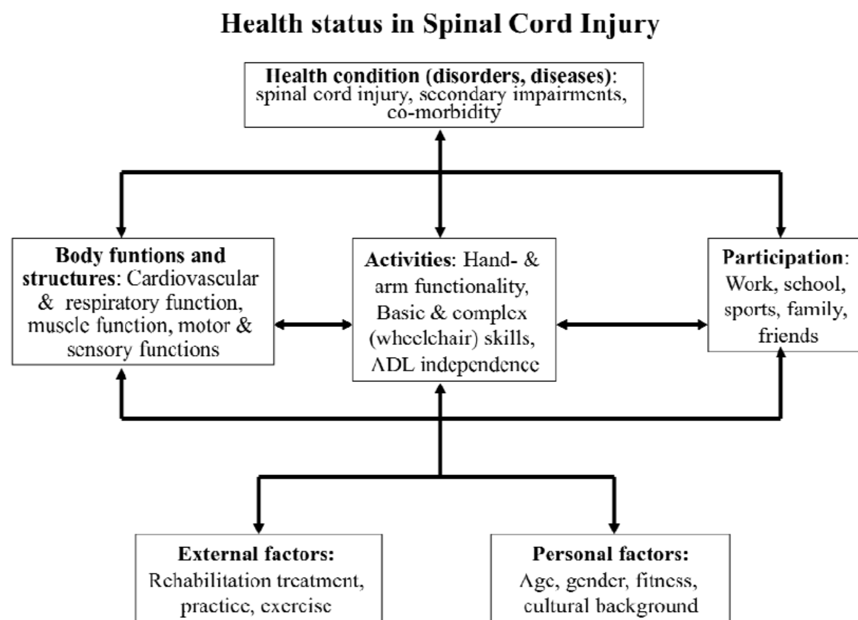

Figure 2.1: An illustration of the interaction of components of the ICF.

2.7 ENVIRONMENTAL FACTORS

Persons living in poor socioeconomic societies are faced with the reality of harsh terrains and poor accessibility to homes and communal areas (Burns & O'Connell, 2012). Such challenges can be complicated by society not realising how important it is for the community to be wheelchair friendly (Burns & O'Connell, 2012). These individuals struggle considerably with accessing transportation to get to their clinic appointments, or to seek medical attention when required (Burns & O'Connell, 2012; Rathore, 2010). The poor accessibility of healthcare services implicated by environmental factors results in patients suffering and even dying prematurely from secondary complications that could have been properly treated or avoided. This challenge can be tackled by sending out a mobile multi-disciplinary team to the communities that are struggling to access medical services (Burns & O'Connell, 2012). Patients' follow-up rates are high as a result of the previously mentioned.

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However, community reintegration can be facilitated by establishing peer support networks, and community-based healthcare workers in the local community that could assist with the patients' long-term wellbeing, by preventing isolation and fostering a sense of community (Burns & O'Connell, 2012).

2.8 REHABILITATION PROCESS AND THE DIFFERENT SYSTEMS OF CARE

South Africa can be described as being both developed and under-developed at the same time; it is home to cosmopolitan city centres, comfortable neighbourhoods and suburbs, but also to impoverished townships (Republic of South Africa, 2015, p.1). The two-tiered healthcare system reflects the same diversity experienced in the country: rehabilitation forms an important part of the management of spinal cord injuries in South Africa, but the quality differs between the two systems with the private sector being better resourced.

The public healthcare system in South Africa is government funded and it is offered to all South African citizens (Young, 2016). It is a two-tiered system divided along socioeconomic lines (Young, 2016). The public system offers all citizens of South Africa access to free health care; however, with the disadvantage of long waiting periods, short, rushed appointments, long follow-up periods, old, outdated facilities, and poor disease control and prevention practices (Young, 2016). Free healthcare benefits those who could not otherwise afford health care (Young, 2016). Citizens can, however, opt to have medical aid or health insurance in order to be treated at private hospitals and health clinics (Young, 2016).

The private healthcare sector, for which one has to pay, has many incentives that set it apart from public health care, such as short waiting periods, short follow-up periods, unhurried appointments, better facilities, and proper disease control and prevention practices (Young,

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2016). South Africa's National Health Insurance, which will be gradually introduced over the next 14 years, proposes to address the inequalities presented by the current private and public systems (Republic of South Africa, 2015).

South Africa has three levels of hospitals: primary, secondary and tertiary (Young, 2016). Primary health care offers limited laboratory services and does not require referrals (Young, 2016). Secondary level hospitals have specific expertise available, such as a rehabilitation centre, including physiotherapy, occupational therapy, orthotics and prosthetics, speech therapy, dietetics, and podiatry (Young, 2016). Tertiary level hospitals offer vastly specialised care due to having the expertise and organisational capacity to deliver evidence-based care (Young, 2016). Patients are transferred to tertiary level hospitals when primary and secondary level care is not adequate to treat a condition (Young, 2016).

In the Netherlands, the healthcare system has a specialised national healthcare system operating on the principles of primary care-led health care and is inclusive of all citizens regardless of their financial, employment, or health status (Van Weel, Schers, & Timmermans, 2012). This system was built on the basis of an already established, strong primary care tradition of family practices with defined populations based on patient panels, practice-based research, evidence-based medicine, large-scale computerisation and robust primary care health informatics (Van Weel et al., 2012). In order to ensure continued quality of care and strategy, a programme for the development and implementation of the system was introduced in 1989 and it is still ensuring quality and safety (Van Weel et al., 2012). The system continues to manage the process of quality and safety improvement (Van Weel et al., 2012). Numerous guidelines have been implemented to ensure that there is correspondence with related educational programmes, patient information, integration with an electronic prescription system, information technology support and a system to support related referrals (Van Weel et al., 2012). A healthcare system that functions effectively in this manner has

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patients that have much better health outcomes than those who do not have the benefit of such a system (Van Weel et al., 2012).

Even though the USA is known for leadership in the field of biomedical research, their astounding medical technology and their specialists, they do not function with National Health Insurance. Consequently, their citizens still have challenges with accessing the healthcare system and the longstanding issues with policy make the foundation of care very weak and flawed (Frew, Joyce, Tanner & Gray, 2008).

Although advances in rehabilitation medicine have improved the mortality and morbidity rates for the population of persons with SCI as a whole, evidence shows that significant disparities occur in rehabilitation outcomes according to differences in individual background and sociodemographic characteristics (Fyffe, Botticello and Myaskoysky, 2011).

These non-uniformed health outcomes from the different healthcare sectors can impose an extra burden on the rehabilitation and reintegration of underserved groups into the community (Fyffe, Botticello and Myaskoysky, 2011). The vulnerable populations are groups who have been historically marginalised in society – the poor, racial and ethnic minorities, women, and older adults – and, therefore, experience a disproportionate amount of exposure to the disadvantages that increase the risk for poorer health and diminished wellbeing (Fyffe, Botticello and Myaskoysky, 2011). Barriers to health and level of care provided influence health outcomes (Frew, Joyce, Tanner & Gray, 2008).

The role of clinicians is to impact every component of the health care process with their knowledge and appropriate treatment regarding the patient's presentation (Fyffe, Botticello & Myaskoysky, 2011). Additionally, clinicians can aid patients in seeking to mitigate the consequences of their vulnerabilities (Fyffe, Botticello & Myaskoysky, 2011). It is hypothesized that the location of service delivery (e.g., local clinic, general practitioner's

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surgery, or specialised rehabilitation or assistive technology centre) will have a significant influence on the role that healthcare providers play on individual outcomes (Fyffe, Botticello & Myaskoysky, 2011). Similarly, the competency of the clinician treating the TSCI patient and prescribing recommendation is critical to assist with optimising the person's functional ability (Fyffe, Botticello & Myaskoysky, 2011).

2.9 SHORTCOMINGS OF GOVERNMENT-FUNDED MEDICAL PRACTICES IN THE DEVELOPING WORLD

2.9.1 Poor evacuation protocols and inadequate pre-hospitalisation care

The ability of co-ordinated healthcare systems to identify and treat all patients with suspected TSCI as medical emergencies, using proper spinal precautions and transporting them efficiently, is the start of an ideal treatment (Middleton, Dayton, Walsh, Katkowsi, Leong & Duong, 2014). A spinal board should be used to immobilise and log roll a suspected SCI patient at the trauma site. In most cases this is not done. The mode of transport is important to prevent further compromise of the spinal cord (Rathore, 2010). Most patients are managed by ambulance staff or bystanders who are not trained to manage a potential SCI (Rathore, 2010). This can be one of the reasons that complete SCI is the most common presentation at admission in the low socioeconomic world (Rathore, 2010).

In low socioeconomic communities' individuals rely on the use of the limited amount of government-funded ambulance services, which are not always able to attend to accidents promptly. On the contrary, privately funded hospital patients make use of their medical aid services to source ambulances that act promptly.

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2.9.2 Inadequate access to advanced radiological imaging techniques

Ordinary radiographers can miss vertebral fractures (Rathore, 2010), especially facet fractures. A detailed evaluation of a suspected SCI requires advanced radiological imaging techniques such as computerised tomographic (CT) scans and magnetic resonance imaging (MRI), to see the extent of damage to the vertebral column and assess the spinal stability (Rathore, 2010). More than half of the developing world does not have access to these advanced radiological imaging techniques (Rathore, 2010). Management based on the plain X-rays of the spine often results in treatment failure and prolonged periods of immobilisation and morbidity of patients (Rathore, 2010).

2.9.3 Access to specialised spinal cord injury wards and centres

Spinal units were established as early as World War 11 in the West (Rathore, 2010). In the developed world, regional and national model SCI centres have been working for the past 50 years (Rathore, 2010). The first 24 hours post TSCI are acknowledged as the most critical for survival, requiring prompt recognition, early evaluation and appropriate management in a suitable setting to achieve maximised outcomes (Middleton, Dayton, Walsh, Katkowsi, Leong & Duong, 2014). Expert consensus recommends expeditious transfer of the suspected TSCI patient (within 24 hours of injury) to a specialised spinal cord injury unit equipped to provide comprehensive, state-of-the-art care by an expert interdisciplinary team (Middleton, Dayton, Walsh, Katkowsi, Leong & Duong, 2014, 2014). Expeditious transfer results in a more rapid diagnosis and intervention with time-critical neurosurgical procedures and emerging pharmacologic therapies that can enhance preservation (neuroprotection) and possible recovery of neurological function and prevent secondary complications (Middleton, Dayton, Walsh, Katkowsi, Leong & Duong, 2014).

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Government-funded hospitals only do operations based on priority, as a result of limited staff and resources. Middleton, Dayton, Walsh, Katkowsi, Leong & Duong, 2014. (2014) found that multiple-trauma SCI patients were more likely to have delays in their admission to an SCI unit and this resulted in 2.5 times greater likelihood for these individuals of suffering from preventable secondary complications. Delayed specialist care is known to increase the occurrence of complications, such as preventable pressure injuries, urinary tract infections, respiratory problems and contractures; potentially increasing morbidity and length of stay, delaying or impeding rehabilitation and adversely affecting long-term wellbeing, function and independence-related outcomes (Middleton, Dayton, Walsh, Katkowsi, Leong & Duong, 2014). SCI patients in government-funded hospitals are treated in the neurosurgical, orthopaedic and general surgical wards with no established protocol for the management and rehabilitation of SCI (Rathore, 2010). Most times treating physicians or surgeons lack the skills of spinal instrumentation or fixation and conservative management (Rathore, 2010). Often, orthopaedic and general surgery takes preference over SCI as there is very little to offer SCI patients (Rathore, 2010).

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2.9.4 Spinal cord injury rehabilitation services in the developing world

Proper SCI rehabilitation is required to reintegrate an individual actively and successfully into the community. In the developed world there is a continuum of care available for all SCI patients as SCI medicine is an established subspecialty in the developed world. Rehabilitation is poorly developed in developing countries. Often, the only healthcare practitioners involved in the rehabilitation of an SCI patient in a government-funded hospital are an orthopaedic surgeon and a physiotherapist (Rathore, 2010). Thus, only exercise, mobility, gait training and the use of assistive devices are attended to (Rathore, 2010). Other equally important aspects of rehabilitation, such as bladder and bowel training, psychological assessment, skin

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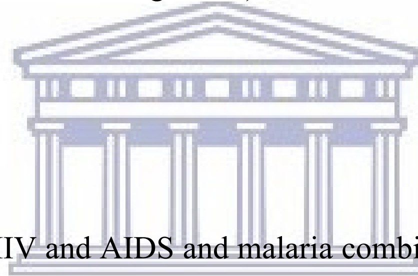
care, sexual dysfunction and fertility management, the addressing of vocation concerns, peer counselling and recreational therapy are neglected.

The current leading causes of poor functional ability in high-income individuals are pneumonia and other respiratory conditions followed by septicaemia, urinary tract and heart diseases (Øderud, 2014). In low-income areas, however, infections and septicaemia caused by urinary tract infections and pressure ulcers are the primary reasons for poor functioning in TSCI individuals (Øderud, 2014). It is important to educate the patients about the risk factors so that self-health is promoted (Rathore, 2010). As a result of the significantly improved availability of pre-hospital treatment more patients arrive at the hospital alive following a TSCI (Hagen, Rekand, Gilhus, & Grønning, 2012).



2.10 CONCLUSION

TSCIs kill more people than HIV and AIDS and malaria combined, and road traffic accidents account for about a quarter of deaths from injuries (Øderud, 2014). More than 90% of deaths that result from injury occur in low- and middle-income countries (Øderud, 2014). Persons with TSCI suffer from secondary complications, such as contractions, pressure ulcers, bladder and bowel complications, autonomic dysreflexia, urinary tract infections, pain syndromes, osteoporosis, bone disorders and heart and respiratory complications (Rathore, 2010). The ICF is a universal framework classification with specified categories that reflects an understanding that the ability to improve functioning is a dynamic and interactive process (Frew, Tanner & Gray, 2008).

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CHAPTER 3: METHODOLOGY

3.1 INTRODUCTION

This chapter contextualises the study setting and the research design implemented for the data collection process. It also provides an overview of the selection of the study population, sampling strategy and the data collection instrument (self-administered questionnaire). A description of the data collection procedure phases is given with results of the pilot study and the reliability study. Lastly, the methods for data analysis and the ethical statement are presented.

3.2 RESEARCH DESIGN

This cross-sectional study was a comparison between two cohorts comprising a government-funded cohort in the Western Cape province and private persons in the Gauteng province. This design provides a snapshot of the patient problems at one point in time without applying an intervention. Specifically, the point prevalence of health status and functioning information was established between the two cohorts with the aim of identifying the most common unmet needs of participants attending different healthcare plans.

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3.3 RESEARCH SETTINGS

The study took place in two provinces. One of the settings was the City of Cape Town metropolitan area in the Western Cape, one of the nine provinces of South Africa. It is situated in the southern part of Africa. Cape Town's population is estimated at 4 004 793 (City of Cape Town, Feb. 2017). This area includes both urban and peri-urban areas and it has one specialised healthcare unit working alongside Tygerberg Hospital (a government-funded tertiary hospital).

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The second setting was Pretoria, a city in Gauteng, South Africa. Gauteng is in the northern part of South Africa and it has a population of 14 717 000. Participants who received rehabilitation at Muelmed Medi-Clinic were invited to take part in this study. I decided to compare two different provinces, one in the north and one in the south of South Africa in order to learn better from two distinct healthcare systems.

3.4 STUDY SAMPLING AND POPULATION

The study population for the Cape Town cohort (government-funded sector) was all persons who sustained their injuries in 2013 and 2014. This was a follow-up of an earlier epidemiologic study (2015 incident paper) (Joseph, Delcarme, Vlok, Wahman, Philips & Wikmar (2015). Altogether 138 persons with TSCI were invited to participate. An inclusive sampling strategy was used. The study population for the Gauteng cohort included 41 conveniently selected participants who had received their rehabilitation at the Muelmed private hospital in 2013/2014. All participants meeting the inclusion criteria were invited to take part in the study and those who consented formed part of the study sample. No *a priori* sample size was calculated, but the respective sample sizes are considered large enough for explorative purposes. Hence, p-values in the results section should be interpreted as exploratory and not be seen as confirmatory in anyway.

3.5 INCLUSION CRITERIA

Participants were included if they fulfilled the following five criteria: 1) confirmed TSCI via magnetic resonance imaging and clinical assessment; 2) they should have completed acute care and in-patient rehabilitation and be in the community; 3) they should be a resident of the

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catchment area; 4) they should be over 18 years of age; 5) they should have provided informed consent.

3.6 EXCLUSION CRITERIA

All patients that presented with diagnosed health conditions other than a TSCI were excluded.

3.7 RESEARCH INSTRUMENT, VALIDITY AND RELIABILITY

This section describes the validity and reliability of all the data-gathering instruments, self-administered questionnaires and standardised outcome measures that were used to collect the data. The International SCI Community (InSCI) questionnaire is a valid standardised instrument used in the study. Permission was granted by the developers for use of the measure in South Africa, specifically in this study. The translated versions were tested for reliability and validity. Due to the demography of patients with SCI, the English version was translated into Afrikaans and IsiXhosa. The original English version of the InSCI questionnaire was forward translated to the respective languages by two independent translators. Following this, the senior researcher, linguist and another translator checked the accuracy and equivalence of the translated versions. All discrepancies were settled in the consensus meeting. Thereafter, the translated questionnaire was interview administered to 20 participants in order to determine any difficulties with the wording (semantics) and underlying experience (experiential equivalence). All of this was done to establish face and content validity. The subscales within the survey present with adequate test-retest reliability, with intraclass correlation coefficients ranging from 0.61-0.89.

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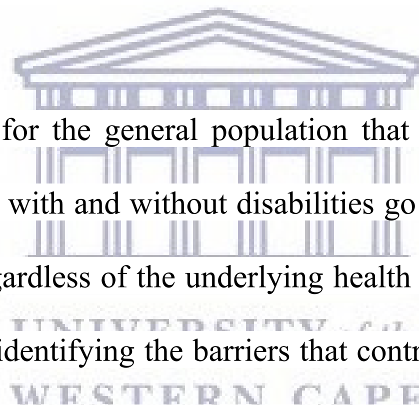
The InSCI questionnaire investigated health problems and services that the participants were able to access in order to manage all SCI-related issues. The questionnaire assessed the level of ease in which the participants were able to function: activities and participation, independence with activities of daily living, their working situation and environmental factors.

The activity and participation section focused on the ease with which household tasks were completed by the participants and their general mobility. These questions were obtained from the Model Disability Questionnaire (MDS) (Trani, Babulal, & Bakhshi, 2015; WHO, 2013) as well as the Spinal cord Injury-Functional Index-Assistive Technologies (SCI-FI-AT) (Jette, Halbert, Iverson, Miceli, & Shah, 2016).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The MDS is a questionnaire for the general population that provides detailed and refined information about how people with and without disabilities go about their daily lives and the challenges they encounter, regardless of the underlying health condition or impairment (Lee, 2018). The MDS assists with identifying the barriers that contribute to the difficulties people encounter, which, in turn, assists with guiding policy and service development (Lee, 2018). The items could be rated as: "No influence", "Made my life a little harder", or "Made my life a lot harder". Furthermore, the MDS also plays an important role in contributing to monitoring the Sustainable Development Goals (Lee, 2018). The MDS is a valid and reliable measure. The MDS assesses activities of daily living, such as the participant's ability to feed, drink, groom, manage bowel and bladder, manage transfers, and mobility. These questions were derived from the Spinal Cord Independence Measure for Self-Report (SCIM-SR), which is also a reliable measure. The reliability coefficient of the SCIM measure is between 0.80 and 0.90 (Siegrist, Reinhardt, Brinkhof & Fekete, 2013).

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The instrument also focuses on whether or not participants are back in their previous employment, whether or not they are satisfied with their work, their working hours, their payment for work, as well as support at work. These work-related questions were sourced from the International Labour Market Integration Assessment in SCI (ILIIAS) (Schottmüller, 2007), the SwiSCI (Swiss Spinal Cord Cohort Study, n.d.) and the MDS (WHO, 2013).

The external or environmental influences were assessed by posing questions related to accessibility to public areas, as well as homes (Ballert, Post, Brinkhof, Reinhardt, & Group, 2015). The attitudes of any persons towards disability which they had encountered were examined (Ballert et al., 2015). Participants' views on transport, lack of assistive devices, medical care and finances were also examined (Ballert et al., 2015). These questions were derived from the Nottwil Environmental Factors Inventory (NEFI) and they demonstrated good internal consistency reliability with an alpha of 0.82 (Ballert et al., 2015).

The construct validity for the above-mentioned instruments was established using the Rasch analysis (Ballert et al., 2015). The Rasch model measures latent traits (e.g., attitude and ability). Latent traits are usually assessed through the responses of a sample of subjects to a set of items. The Rasch model belongs to the item response theory models. The entire self-administered questionnaire comprised 125 questions, which took approximately 45 minutes to complete. The questionnaire was translated into IsiXhosa and Afrikaans for those participants who did not understand English.

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3.8 PROCEDURE

Prior to the administration of the questionnaire, ethical clearance was granted from the Biomedical Research Ethics Committee. Each individual with TSCI on the two databases (consisting of 138 individuals in each cohort) was invited to participate in the study on

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condition that they still met the inclusion criteria. If they chose to participate in a face-to-face interview, information sheets and consent forms were given to them and explained prior to the commencement of the study. They also had an option to complete the questionnaire telephonically with a research assistant prompting them. In the case of a telephonic interview, an information sheet was sent to them via email or another platform (postal mail), while their consent statement was audio recorded, as commonly performed in social sciences research of this nature. This approach of confirming consent was approved by the institution's ethics committee. Participants also had the choice to complete the questionnaire in two sittings. Since the questionnaire is quite extensive, they were allowed to complete it within one week to ensure that their health status did not change. Due to the extensiveness of the questionnaire, there are missing data from some questionnaires. It was, however, decided to retain these data sets as more than 80% of the questions were answered. No data imputation was done. Possible reasons for missing data are that the participants either did not understand the questions when completing the questionnaire, or they could not remember the answer. An attempt was made to gain missing data, but it was not always possible as we could not always get hold of the participants.

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3.9 DATA ANALYSIS

The data were captured on an Excel spreadsheet and then transferred to version 25 of SPSS for analysis. Objectives 1 to 4 were analysed descriptively in order to provide an overview of the study. Thereafter, inferential statistics, such as the Chi Square for categorical variables and the Mann-Whitney U test or independent student t-test, were used to assess differences in patient characteristics, health status, activity limitations, participation restrictions and environmental factors between the two cohorts.

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3.10 ETHICS

Ethical clearance to conduct the study was sought from the Biomedical Research Ethics Committee of the University of the Western Cape. The study was conducted according to ethical practices pertaining to the study of human subjects. Participation in the study was voluntary and the participants had the right to withdraw at any time. Risks were mitigated by providing informed consent, not breaching confidentiality of sensitive information and using procedures that are consistent with research that do not expose participants to risks. In addition, there was no direct, foreseeable risk associated with the study. However, minimal risks could not be exempted. Minimal risks could have been caused when asking participants sensitive questions regarding their health status and functioning. If they did become distressed or emotional, the researcher would have recommended appropriate steps to be taken to consult a health professional.

In all phases of the study an information sheet was provided to all participants to give them a clear understanding of the project and what it entails. All participants signed a consent form prior to inclusion. The information gathered was kept anonymous by using coding and/or pseudonyms. Confidentiality was ensured throughout the project. The results would be made available to participants in order for them to assess their status with respect to their peers and the departments of health in the Western Cape and Gauteng.

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3.11 CONCLUSION

This cross-sectional study was a comparison between two cohorts comprising a government-funded cohort in the Western Cape province and private persons in the Gauteng province. This study took place in two provinces in South Africa, Gauteng and the Western Cape. The International SCI Community (InSCI) questionnaire is a valid standardised instrument used in the study. Permission was granted by the developers for

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use of the measure in South Africa, specifically in this study. The data were captured on an Excel spreadsheet and then transferred to SPSS for analysis. Ethical clearance to conduct the study was sought from the Biomedical Research Ethics Committee of the University of the Western Cape. The study was conducted according to ethical practices pertaining to the study of human subjects.

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CHAPTER 4: RESULTS

4.1 INTRODUCTION

This section presents the results of the study according to the five objectives. All the data presented is a comparison between the two cohorts. All the results are mentioned according to the 5 objectives of the study, namely epidemiology, activity limitation, participation restriction, secondary complications and, finally, environmental restrictions.

4.2 OBJECTIVE 1: EPIDEMIOLOGY

Included in this study were 41 participants from the private cohort and 97 participants from the public cohort. Males were more common in both cohorts. Concerning participants' characteristics, a significant association in the distribution of marital status (P=0.006), injury aetiology (p=0.001) and level of injury (0.005) was found between the sectors in that those in the public cohort were mostly single, their injuries were predominantly due to gunshots and their level of lesion mainly caused paraplegia, whereas the private cohort consisted largely of male participants and their injuries were mainly caused by traffic accidents. There was also a significant association in the distribution regarding the highest level of education (p=0.001) between the two cohorts. The private cohort has 70.73% of TSCI individuals that completed tertiary education compared to the 27.59% in the public cohort. There is no significant difference of the ages between the two cohorts, the private cohort has an average age of 38.3 and the public cohort has an average age of 44. There were, however, no significant differences in the distribution of gender and completeness of injury noted between the two cohorts.

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Table 4.1 The epidemiological characteristics of the participants

	PUBLIC SECTOR			PRIVATE SECTOR			*P*
TOTALS	***n=97***	***%***	***MD***	***n=41***	***%***	***MD***	
GENDER							
Male	73	78.5		27	65.9		
Female	20	21.5		14	34.1		
AGE	38.3			44			
MARITAL STATUS							
Single	68	70.8		28	69.2		
Married	10	10.6		13	31.7		
Cohabitating	9	9.6		0	0		
Separated or divorced	6	6.4		0	0		
Widowed	1	1.1		0	0		
Total	94	100	3	41	100	0	
LEVEL OF INJURY							
Paraplegic	58	63		15	36.6		
Tetraplegic	34	37		26	63.4		
Total	92	100	5	41	100	0	
COMPLETENESS OF INJURY							
Complete	27	29		15	36.6		
Incomplete	66	71		26	63.4		
Total	93	100	4	41	100	0	
AETIOLOGY							
Accident leisure/sports	14	14.7		8	19.5		
Injury due to violence	45	47.4		6	14.6		
Traffic accident	32	33.7		19	46.3		
Accident during work	1	1.1		3	7.3		
Fall from a height	3	3.2		5	12.2		
Total	95	100	2	41	100	0	
DISEASE DURATION							
Mean	8.11			11.7			
Median	4			9.5			
Std. deviation	9.709			11.5			
Min; Max	1-40y			1-4y			

MD=Missing data; P= P value significance at 0.05

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4.3 OBJECTIVE 2: ACTIVITY LIMITATIONS

Overall, differences in functional independence were noted between the two cohorts. Specifically, significant differences in the following were found between the cohorts, with the private cohort appearing to be more independent: the execution of grooming (P=0.049), turning of the lower body (P=0.014), moving around moderate distances (P=0.001), grooming (p=0.049), use of external drainage instruments (p=0.003), bowel management (p=0.050), turning the lower body in bed (p=0.014), sitting up in bed (p=0.014), doing a push-up in a chair (p=0.028), wheelchair to bed transfer (p=0.018), moving moderate distances (p=0.001).

No statistical differences in the execution of the following activities were noted: dressing lower body in bed (p=0.468), intermittent catherization (p=0.159) and turning the upper body (p=0.179).

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Table 4.2 The activity limitations of the participants

	PUBLIC SECTOR			PRIVATE SECTOR			P
TOTALS	***n=97***	***%***	***MD***	***n=41***	***%***	***MD***	
DRESSING LOWER BODY							0.468
Needs total or partial assistance	43	45.2		13	31.7		
Independent, with AD	3	3.2		2	4.9		
Independent	49	51.6		26	63.4		
Total	95	100	2	41	100	0	
GROOMING							0.049
Needs total or partial assistance	34	36.1		6	14.7		
Independent, with AD	5	5.3		1	2.4		
Independent	55	58.5		34	82.9		
Total	94	100	3	41	100	0	
INTERMITTENT CATHERTERISATION							0.159
Needs total or partial assistance	25	30.1		6	14.6		
Completely independent	11	13.3		21	51.2		
Does not use it	47	56.6		14	34.1		
Total	83	100	14	41	100	0	
EXTERNAL DRAINAGE INSTRUMENTS							0.003
Needs total or partial assistance	27	32.2		5	12.2		
Completely independent	10	11.9		13	31.7		
Continent with urine	39	34.5		25.5	24.4		
Not applicable	18	21.4		13	31.7		
Total	84	100	13	41	100	0	
ASSISTANCE WITH BOWEL MANAGEMENT							0.050
Yes	50	55.6		17	41.5		
No	40	44.4		24	58.69		
Total	90	100		41	100		
BOWEL MANAGEMENT							
Irregular (<3 days)	27	32.5		2	4.9		
Regular (Once in 3 days)	56	67.5		39	95.1		
Total	83	100	14	41	100		
FECAL INCONTINENCE							0.009
Daily	3	3.3		1	2.4		
1-6 times a week	11	12.1		9	22		
1-4 times a week	16	17.6		5	12.2		
Less than a month	20	22		18	43.9		
Never	41	45.1		8	19.5		
Total	91	100	0	41	100	0	
TURNING UPPER BODY IN BED							0.179
Able	60	47.9		31	75.6		
Unable	34	52.1		10	24.4		
Total	94	100	3	41	100	0	
TURNING LOWER BODY IN BED							0.014
Able	45	47.9		29	70.7		
Unable	49	52.1		12	29.3		
Total	94	100	3	41	30.4	0	

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SITTING UP IN BED							
Able	45	47.9		29	70.7		
Unable	49	52.1		12	29.3		
Total	94	100	3	41	100	0	
DOING PUSH-UPS IN A CHAIR OR WHEELCHAIR							0.028
Able	38	40.4		25	61		
Unable	56	59.6		16	39		
Total	94	100	3	41	100	0	
WHEELCHAIR TO BED TRANSFER							0.018
Needs total or partial assistance	44	46.8		15	36.6		
Independent in wc	25	26.6		20	48.8		
Does not use a wc	25	26.6		6	14.6		
Total	94	100	3	41	100	0	
MOVING AROUND MODERATE DISTANCES WITH WHEELCHAIR							0.001
Needs total or partial assistance	34	36.2		8	19.5		
Independent in manual wc	36	38.3		25	61		
Not applicable	24	25.5		8	19.5		
Total	94	100	3	41	100		

WC= wheelchair; MD= missing data; P= P value; AD=adaptive devices

4.4 OBJECTIVE 3: PARTICIPATION RESTRICTION

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Numerous differences were noted between the level of participation of the two cohorts. Significant differences in the distribution of the following activities were present between cohorts, with the private cohort having a higher proportion of “no problem” with participation in these activities: carrying out daily routine (p=0.000), getting to where they want to be (p=0.008), using public transport (p=0.000), using private transport (0.000), providing care and support for others (p=001), interacting with people (p=0.024), ability to sit unsupported (p=0.004), ability to stand unsupported (p=0.055) and pushing open a heavy door (p=0.002).

However, no difference was found in the association in the following: handling stress (p=0.499), doing activities that require the use of hands (p=0.153), intimate relationships (p=0.186), doing things for relaxation and pleasure (p=0.245), problems with sitting

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unsupported (p=0.423), getting up from the floor (p=0.712), moving from sitting at the side of the bed when lying down on one's back (p=0.178).

With regard to careers and vocational training there was a significant difference between the engagement in paid work (p=0.000) and current working situation, with the private sector being more engaged in paid work. Likewise, more of the participants from the private sector were working for a wage or salary and were self-employed. There was, however, no significant difference between the amount of vocational training received post injury (p=0.163) between the two cohorts. Thirty-four individuals from the private cohort noted that the main reasons for not being engaged in work in the private sector were that they could not find suitable work and their health condition or disability (24.07%) in the public sector. Twenty-two per cent of the private cohort were self-employed and 48.8% of the private cohort were earning a salary or wage. The public cohort reflected an unemployment percentage of 79.6% compared to the 17.2% unemployment in the private cohort. Lastly, the private cohort appeared to be more independent in the execution of activities and social roles compared to the public cohort.

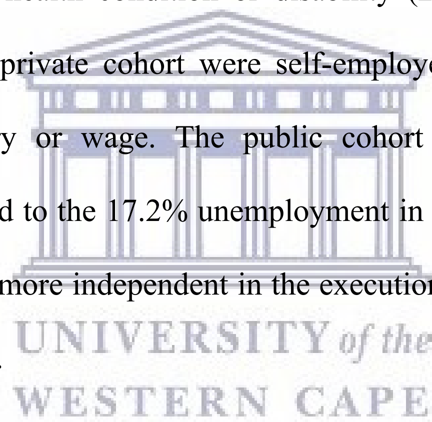
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Table 4.3 Participation restriction of participants

	PUBLIC SECTOR			PRIVATE SECTOR			P
TOTALS	***n=97***	***%***	***MD***	***n=41***	***%***	***MD***	
DAILY ROUTINE							0.000
No problem	37	39.4		29	70.7		
Some problem	26	27.7		11	26.8		
Extreme problem	31	33		1	2.4		
Total	94	100	3	41	100	0	
HANDLING STRESS							0.499
No problem	32	33.7		17	41.5		
Some problem	57	60		23	56.1		
Extreme problem	6	6.3		1	2.4		
Total	95	100	2	41	100	0	
ACTIVITIES REQUIRING							0.153

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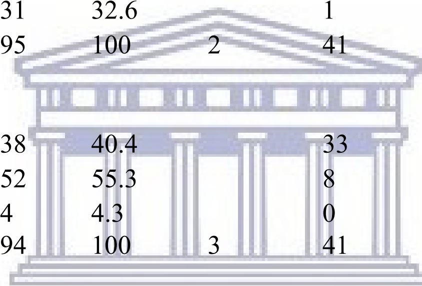
HAND USE							
No problem	43	45.3		22	53.7		
Some problem	29	30.5		15	36.6		
Extreme problem	23	24.2		4	9.8		
Total	95	100	2	41	100	0	
GETTING TO WHERE YOU WANT TO GO							0.008
No problem	34	35.8		24	58.5		
Some problem	29	3.5		13	31.7		
Extreme problem	32	33.7		4	9.8		
Total	95	100	2	41	100	0	
USING PUBLIC TRANSPORTATION							0.000
No problem	31	33.3		38	95		
Some problem	19	20.4		1	2.5		
Extreme problem	43	46.2		1	2.5		
Total	93	100	4	40	100	1	
USING PRIVATE TRANSPORTATION							0.000
No problem	36	37.9		33	80.5		
Some problem	28	29.5		7	17.1		
Extreme problem	31	32.6		1	2.4		
Total	95	100	2	41	100	0	
LOOKING AFTER YOUR OWN HEALTH							0.000
No problem	38	40.4		33	80.5		
Some problem	52	55.3		8	19.5		
Extreme problem	4	4.3		0	0		
Total	94	100	3	41	100	0	
GETTING HOUSEHOLD TASKS DONE							0.000
No problem	39	41.5		31	75.6		
Some problem	55	58.5		9	22		
Extreme problem	0	0		1	2.4		
Total	94	100	3	41	100	0	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PROVIDING CARE AND SUPPORT FOR OTHERS							0.001
No problem	43	45.7		32	78		
Some problem	41	43.6		9	22		
Extreme problem	10	10.6		0	0		
Total	94	100	3	41	100	0	
INTERACTING WITH PEOPLE							0.024
No problem	56	60.2		42	82.9		
Some problem	31	33.3		7	17.1		
Extreme problem	6	6.5		0	0		
Total	93	100	4	41	100	0	
INTIMATE RELATIONSHIPS							0.186
No problem	43	46.2		26	63.4		
Some problem	40	43		12	29.3		

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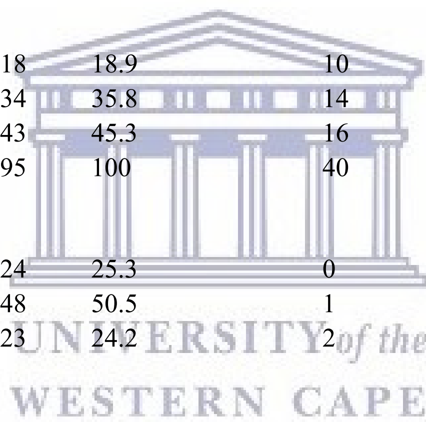
Extreme problem	10	10.8		3	7.3		
Total	93	100	4	41	100	0	
DOING THINGS FOR RELAXATION AND PLEASURE							0.245
No problem	50	52.6		28	68.3		
Some problem	37	38.9		26.8	65.4		
Extreme problem	8	8.4		2	4.9		
Total	95	100	2	41	100	0	
ABILITY TO SIT UNSUPPORTED							0.004
No	43	45.3		8	19.5		
Yes	52	54.7		33	80.5		
Total	95	100	2	41	100	0	
PROBLEMS WITH SITTING UNSUPPORTED							0.423
No problem	31	32.7		17	41.5		
Some problem	22	23.2		12	29.3		
Extreme problem	9	9.5		4	9.8		
Not applicable	33	34.7		8	19.5		
Total	95	100	2	41	100	0	
GETTING UP FROM THE FLOOR							0.712
Without any difficulty	18	18.9		10	25		
With some difficulty	34	35.8		14	35		
With much difficulty	43	45.3		16	40		
Total	95	100		40			
PUSHING OPEN A HEAVY DOOR							0.002
Without any difficulty	24	25.3		0	41.5		
With some difficulty	48	50.5		1	58.5		
With much difficulty	23	24.2		2	0		
Total							
MOVING FROM SITTING AT THE SIDE OF THE BED TO LYING DOWN ON YOUR BACK							0.178
Without any difficulty	42	44.2		10	53.7		
With some difficulty	22	23.2		14	29.3		
With much difficulty	31	32.6		16	17.1		
Total	95	100	2	40	100	0	
DID YOU RECEIVE VOCATIONAL TRAINING POST INJURY?							0.163
Yes	52	57.8		17	46.3		
Not applicable	0	0		24	2.4		
Total	90	100	7	0	100	0	
WORKING STATUS					48.8		
Working for wages or salary	13	14			22		
Self-employed	5	5.4		22	2.4		
Student	1	1.1		12	17.1		
Unemployed	74	79.6		7	9.8		
Retired due to health condition	0	0		41	100	0	
Total	93	100	4				
ENGAGEMENT IN PAID				19	61		0.000



WORK							
Yes	17	18.5		1	36.6		
No	67	72.8		41	2.4		
Not applicable	8	8.7		20	100	0	
Total	92	100	3				
REASONS FOR NOT WORKING							
Health condition or disability	41	24.7		25	13.8		0.005
Personal family responsibilities	4	2,4		15	0		0.173
Could not find suitable work	34	20.5		1	62.1		0.000
Do not have a financial need	4	2.4		41	3.5		0.586
Parents or spouse did not let me work	4	2.4			3.45		0.931
Insufficient transportation services	2	1.2		8	3.5		0.030
Lack of accessibility	14	8.4		0	5.2		0.200
Lack of assistive devices	14	8.4		36	3.5		0.242
Fear of losing disability pension	7	2.2		1	3.5		0.324
I do not want to work	6	3.6		1	0		0.173
Other	4	2.4		1	3.5		0.134

MD= Missing data; P=P value

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4.5 OBJECTIVE 4: SECONDARY COMPLICATIONS

There was a significant association between the point prevalence secondary complications between cohorts, specifically related to: contractures (p=0.000), muscle spasm (p=0.042), respiratory problems (p=0.032) autonomic dysreflexia (p=0.001) and postural hypotension (0.037). Generally, the private cohort experienced than far fewer problems than the public cohort in the "No problem" category in the secondary complications section.

However, there was no significant association between the following secondary complications: sleeping problems (p=0.202), bowel dysfunction (p=0.482), urinary tract infection (0.087), bladder dysfunction (p=0.079), sexual dysfunction (p=0.090), muscle spasm (p=251), pressure ulcers (p=0.164), injury caused by loss of sensation (p=0.962), circulatory problems (p=0.799) and pain (p=0.078). The three most highly rated in the "Severe problem" category, in the private cohort were: pain (34.1%), muscle spasm (29.3%) and urinary tract infection (24.4%). The three highest in this category in the public cohort were: muscle spasm (20.2%), pain (20.2%) and circulatory problems (11.6%).

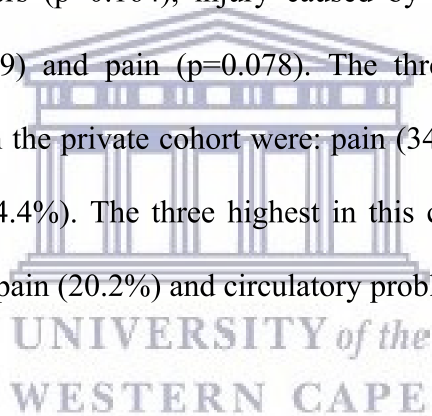
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Table 4.4 Prevalence of secondary medical complications between cohorts

	PUBLIC SECTOR			***PRIVATE SECTOR***			***P***
TOTALS	***n=97***	***%***	***MD***	***n=41***	***%***	***MD***	
SLEEPING PROBLEM							0.202
No problem	36	37.9		21	51.2		
Few problems	43	45.3		13	23.2		
Severe problems	4	4.2		0	0		
Total	83	100	14	34	100	7	
BOWEL DYSFUNCTION							0.482
No problem	41	44.1		19	46.3		
Few problems	44	47.3		16	39		
Severe problems	8	8.6		6	14.6		
Total	60	100	31	41	100	0	
URINARY TRACT INFECTION							0.087
No problem	46	48.9		29	70.7		
Few problems	37	39.4		10	24.4		
Severe problems	5	5.3		0	0		
Total	88	100	13	39	100	2	
BLADDER DYSFUNCTION							0.079
No problem	43	46.2		23	67.6		
Few problems	38	40.9		11	32.4		
Severe problems	5	5.4		0	0		
Total	86	100	11	34	100	7	
SEXUAL DYSFUNCTION							0.090
No problem	39	54.9		24	77.4		
Few problems	29	40.9		7	22.6		
Severe problems	6	8.45		0	0		
Total	71	100	26	31	100	10	
CONTRACTURES							0.000
No problem	37	41.6		32	86.5		
Few problems	47	52.8		5	13.5		
Severe problems	5	5.6		0	0		
Total	89	100	8	37	100	4	
MUSCLE SPASM							0.251
No problem	17	18.1		10	24.4		
Few problems	58	61.7		19	46.3		
Severe problems	19	20.2		12	29.3		
Total	94	100	3	41	100	0	
PRESSURE ULCERS							0.164
No problem	66	70.2		35	85.4		
Few problems	21	22.3		5	12.2		
Severe problems	7	7.4		1	2.4		
Total	94	100	3	41	100	0	

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RESPIRATORY PROBLEMS							0.032
No problem	61	65.6		35	85.4		
Few problems	23	24.7		6	14.6		
Severe problems	9	9.7		0	0		
Total	83	100	14	41	100	0	
INJURY CAUSED BY LOSS OF SENSATION							0.962
No problem	72	80		33	80.5		
Few problems	15	16.7		7	17.1		
Severe problems	3	3.3		1	2.4		
Total	90	100	7	41	100	0	
CIRCULATORY PROBLEMS							0.799
No problem	48	50.5		19	46.3		
Few problems	36	37.9		18	43.9		
Severe problems	11	11.6		4	9.8		
Total	95	100	2	41	100	0	
AUTONOMIC DYSREFLEXIA							0.001
No problem	35	37.2		29	70.7		
Few problems	49	52.1		8	19.5		
Severe problems	10	10.6		4	9.8		
Total	94	100	3	41	100	0	
POSTURAL HYPOTENSION							0.037
Few problems	41	44.1		10	24.4		
Severe problems	6	6.5		1	2.4		
Total	93	100	4	41	100	0	
PAIN							0.078
No problem	19	20.2		11	26.8		
Few problems	56	59.6		16	39		
Severe problems	19	20.2		14	34.1		
Total	94	100	3	41	100	0	
PAIN SCALE (VAS) in the last 4 weeks	94	Mean: 66.45		42	Mean: 73.08		0.360

MD= missing data; P= P value

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4.6 OBJECTIVE 5: ENVIRONMENTAL RESTRICTIONS AND QUALITY OF LIFE

There was a significant association between cohorts with respect to the following environmental factors: missing or insufficient accessibility to public places ($p<0.000$), missing or insufficient accessibility to home of friends or relatives ($p=0.000$), unfavourable weather conditions ($p=0.003$), negative societal attitudes ($p=0.010$), negative attitudes of family and relatives ($p=0.000$), lack of or insufficient adapted assistive technology for moving around short and long distances ($p=0.000$), lack of or insufficient nursing care and support services ($p=0.000$), lack of or insufficient medical and medical aids ($p=0.000$), problematic financial situation ($p=0.000$), lack of or insufficient communication devices ($p=0.004$) and lack of state services ($p=0.000$). There was no significant difference between cohorts with respect to negative attitude of friends ($p=0.225$), neighbours, acquaintances and colleagues towards (0.202%) their disabilities that made their lives harder.

Problematic financial situations and insufficient adapted assistive technology for moving around long distances (43.2%), missing or insufficient access to public places (34.7%) and lack of or insufficient communication devices (30.9%) were the highest environmental limitations in the public cohort. Lack of or insufficient communication devices (50%), lack of or insufficient state services (40.5%) and negative societal attitudes (9.76%) were of the highest environmental limitations noted in the private cohort.

The private cohort rated the quality of life option for very good as 36.58% compared to the public cohort 6.7%, with a significant difference ($p= 0.0001$).

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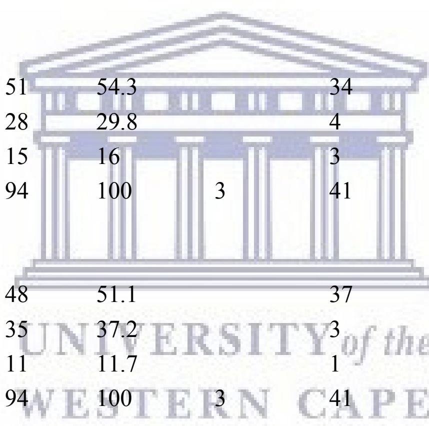
Table 4.5 Environmental barriers and quality of life

	PUBLIC SECTOR			PRIVATE SECTOR			P
TOTALS	***n=97***	***%***	***MD***	***n=41***	***%***	***MD***	
ACCESSIBILITY OF PUBLIC PLACES							0.000
No influence	30	31.6		41	100		
Made my life a little harder	33	34.7		0	0		
Made my life a lot harder	32	34.7		0	0		
Total	95	100	2	41	100	0	
ACCESSIBILITY TO HOMES OF FRIENDS AND RELATIVES							0.000
No influence	35	78.4		33	80.5		
Made my life a little harder	29	31.2		8	19.5		
Made my life a lot harder	29	31.2		0	0		
Total	93	100	4	42	100	0	
UNFAVOURABLE CLIMATIC CONDITIONS							0.003
No influence	33	35.9		28	66.7		
Made my life a little harder	39	42.4		11	26.2		
Made my life a lot harder	20	21.7		3	7.1		
Total	92	100	5	41	100	0	
NEGATIVE SOCIETAL ATTITUDES							0.010
No influence	51	54.3		34	82.9		
Made my life a little harder	28	29.8		4	9.8		
Made my life a lot harder	15	16		3	7.3		
Total	94	100	3	41	100	0	
NEGATIVE ATTITUDES OF FAMILY AND RELATIVES							0.000
No influence	48	51.1		37	90.2		
Made my life a little harder	35	37.2		3	7.3		
Made my life a lot harder	11	11.7		1	2.44		
Total	94	100	3	41	100		
NEGATIVE ATTITUDE OF FRIENDS TOWARDS DISABILITY							0.225
No influence	58	61.1		31	75.6		
Made my life a little harder	26	27.4		8	19.5		
Made my life a lot harder	11	11.6		2	4.9		
Total	95	100	2	41	100	0	
NEGATIVE ATTITUDE OF NEIGHBOURS, ACQUAINTANCES AND COLLEAGES							0.202
No influence	64	67.4		27	65.9		
Made my life a little harder	22	23.2		14	42	c	
Made my life a lot harder	9	9.5		0	0		
Total	95	100	2	41	100	0	
LACK OF OR INSUFFICIENT ADAPTED ASSISTIVE TECHNOLOGY FOR MOVING AROUND SHORT DISTANCES							0.000
No influence	45	47.4		36	87.8		
Made my life a little harder	22	23.2		4	9.8		
Made my life a lot harder	28	29.5		1	2.4		
Total	95	100	2	41	100	0	



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INSUFFICIENT ADAPTED ASSISTIVE TECHNOLOGY FOR MOVING AROUND LONG DISTANCES							0.000
No influence	38	40		33	80.5		
Made my life a little harder	16	16.8		5	12.2		
Made my life a lot harder	41	34.7		3	7.4		
Total	95	100	2	41	100	0	
LACK OF OR INSUFFICIENT NURSING CARE AND SUPPORT SERVICES							0.000
No influence	51	53.7		41	100		
Made my little harder	26	27.4		0	0		
Made my life a lot harder	18	18.9		0	0		
Total	95	100	2	41	100	0	
LACK OF INSUFFICIENT MEDICATION AND MEDICAL AIDS							0.000
No influence	47	50.5		41	100		
Made my life a little harder	34	36.6		0	0		
Made my life a lot harder	12	12.9		0	0		
Total	93	100	4	41	100	0	
PROBLEMATIC FINANCIAL SITUATION							0.000
No influence	15	15.8		12	29.3		
Made my life a little harder	39	41.1		29	70.7		
Made my life a lot harder	41	43.2		0	0		
Total	95	100	2	41	100	0	
LACK OF OR INSUFFICIENT COMMUNICATION DEVICES							0.004
No influence	47	50		21	51.2		
Made my life a little harder	18	19.1		0	0		
Made my life a lot harder	29	30.9		20	48.8		
Total	94	100	3	41	100	0	
LACK OF OR INSUFFICIENT STATE SERVICES							0.000
No influence	44	47.3		25	61		
Made my life a little harder	29	31.2		0	0		
Made my life a lot harder	20	21.5		16	39		
Total	93	100	4	41	100	0	
QUALITY OF LIFE							0.0001
Very poor	6	6.7		2	2.4		
Poor	5	5.6		0	0		
Neither poor nor good	24	30		7	17.1		
Good	48	53.3		18	43.9		
Very good	6	6.7		15	36.6		
Total	89	100	8	41	100	0	

MD= Missing data; P= P value

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CHAPTER 5: DISCUSSION OF THE RESULTS

5.1 INTRODUCTION

This chapter presents the results of the study as it reports on the research questions and the objectives. The aim of the study was to determine the health status and functioning of TSCI patients in a public sector cohort in the Western Cape and a private sector cohort in Gauteng. In this chapter, epidemiology, activity limitation, participation restrictions, secondary complications, environmental factors and quality of life are discussed in relation to current literature. Literature from both local and international perspectives is utilised.

5.2 EPIDEMIOLOGY

5.2.1 Gender, age and marital status

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It was found in this study that there are more male TSCI patients in the public sector, due to assault aetiology being more common in this cohort. In the private sector fewer men were found to be affected. However, in the private sector more women were affected than in the public sector. The public cohort's socioeconomic status was lower than that of the private cohort; usually in these communities the woman stays at home to take care of the family (Øderud, 2014), which exposes the men more to potentially sustaining a TSCI (Øderud, 2014). In the private sector – the more economically developed community – it was found that more women had sustained a TSCI compared to the public cohort. This agrees with the findings of Øderud (2014), namely that women are slowly catching up with the trends and lifestyles of men and more of them are driving their own cars and can be seen as self-efficient. However, this trend exposes women more to the possibility of sustaining a TSCI, compared to the women in the public cohort. A significantly higher divorce rate was found to

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exist in the public sector, with more of the public cohort being single compared to the private healthcare sector.

5.2.2 Aetiology, injury duration level and completeness of injury

There was a significant difference in the aetiology of injury; with the private sector's main aetiology being traffic accidents and the public sector's being violence. These findings are in line with previous studies that found the main cause of TSCI in South Africa to be gunshot wounds and traffic accidents (Øderud, 2014; Moodley & Pillay, 2013; Burns & O'Connell, 2012; Joseph, 2016; Hart & Williams, 2014). The fact that women are more productive and active in society than men explains why the private cohort has more women, because more women are driving their own cars, hence they are more at risk of sustaining a TSCI. A significant association was found between the level of injury between cohorts. The private cohort had significantly more tetraplegic injuries, compared to the public cohort with significantly more paraplegic injuries. The mechanism of injury in a traffic accident increases the likelihood of sustaining a tetraplegic TSCI when a seat belt is not utilised while travelling by car (Schültke, 2011).

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These results confirm the importance of educating the public to create awareness and having strategies in place to prevent these injuries. Prevention plays a crucial role in decreasing the incidence and severity of spinal cord injury (Schültke, 2011). Furthermore, public awareness of risk factors leading to spinal cord injuries, the introduction of the obligatory use of safety belts and the installation of air bags in cars are also aimed at decreasing trauma severity and the completeness of the spinal cord injury (Schültke, 2011).

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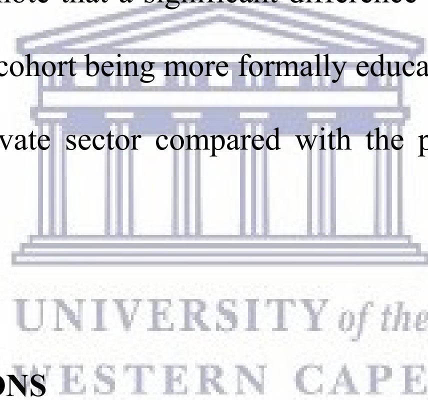
Improvements in and the prioritising of pre-hospital care, inclusive of principles of first aid and the introduction of the principle of spinal cord immobilisation during rescue and transport could help to reduce additional injury sustained after initial trauma and it could play an imperative role in preventing the compromise of the integrity of the already damaged spinal cord (Schültke, 2011). Incorrect pre-hospital care could cause even more damage.

5.2.3 Years of educational training and perceived financial status

The perceived financial status of the private sector was found to be significantly higher than that of the public cohort. There is a connection between financial status and level of education. It is interesting to note that a significant difference was found between the years of education, with the private cohort being more formally educated. The incidence of TSCI is significantly lower in the private sector compared with the public-funded sector (Joseph, 2016).



5.3 ACTIVITY LIMITATIONS

Based on the results, it is evident that the private cohort were more independent in their activities, specifically with the execution of grooming, turning the lower body in bed, moving around moderate distances, use of external drainage instruments, bowel management, sitting up in bed, doing a push-up in a chair, wheelchair to bed transfers and mobilising in wheelchairs for moderate distances. Their extensive and specialised rehabilitation was helpful in attaining these functional levels. A study done in Australia agrees that TSCI individuals rehabilitated by a specialised institution, as in the private cohort, are significantly less disabled than those not rehabilitated by a specialised system (Simmonds & Stevermuer, 2011).

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A study done in Sweden showed a moderate level of activity limitation, depending on their level of injury and spasticity explained 68% of the activity limitation (Jörgensen, Iwarsson & Lexell, 2017). Activity limitations in this study were not associated with gender, age and time since injury, instead life satisfaction, was another important factor affecting the activity limitation apart from the level of the TSCI (Jörgensen, Iwarsson & Lexell, 2017). This international study notes that marital status, employment, bladder function and the characteristics of the injuries affected life satisfaction most (Jörgensen, Iwarsson & Lexell, 2017). Older individuals with long-term SCI are able to maintain higher levels of physical independence satisfaction in their life, irrespective of gender, age or injury duration. With that said, the private cohort has more favourable conditions for promoting an increased level of functioning compared to the public cohort.

There was, however, no significant difference between the following activities of the two cohorts: dressing the lower body, intermittent catheterisation and turning the upper body in bed. These activities are usually complicated by the completeness and level of injury and not so much by the rehabilitation process. It is important that all TSCI individuals have access to specialised care to optimise their physical potential (Simmonds & Stevermuer, 2011).

5.4 PARTICIPATION RESTRICTIONS

5.4.1 Transport

The private cohort had better access to public transport, as well as to private transport, and they found it less difficult to reach their desired destination than the public cohort. The private cohort could afford to modify their personal cars to better suit their needs, making them more independent and less affected by the transport struggles faced by the public cohort. The public cohort has challenges with accessing public transport as they are faced

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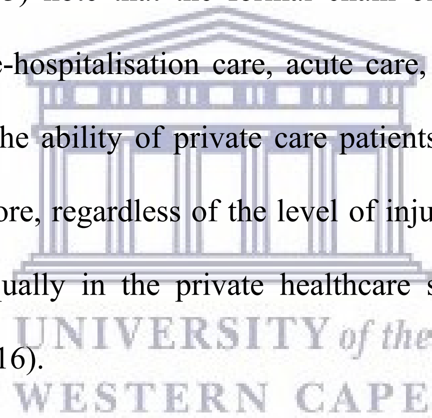
with harsh terrains that are not wheelchair-friendly, especially in the rural communities, and most of them do not possess their own car (Burns & O'Connell, 2012).

5.4.2 Physical factors

The private cohort's patients were significantly more able to stand, sit unsupported and push open a heavy door. This is interesting to note, taking into consideration that the private healthcare sector had 7.6% more complete spinal cord injuries and 7.6% fewer incomplete injuries. The question arises: what exactly contributed to this improved ability of the private cohort to stand, sit and push open a heavy door more effectively than the public cohort? Rahimi-Movaghar et al. (2013) note that the formal chain of care utilised in the private sector, starting with good pre-hospitalisation care, acute care, rehabilitation and outpatient care, plays a pivotal role in the ability of private care patients to function on the level on which they should be. Therefore, regardless of the level of injury and completeness thereof, each patient is prioritised equally in the private healthcare system, unlike in the public healthcare system (Joseph, 2016).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5.4.3 Social and emotional factors

The private cohort was more independent and efficient in being able to provide care and support for others and interacting with others. However, no significant differences were found between the cohort's ability to handle stress and doing things for relaxation and pleasure. These factors largely affect these persons' ability to participate and be reintegrated into society, hence the private cohort was more independent with regard to the above-mentioned because their socioeconomic status made it more beneficial for them to so do (Rathore, 2010). The more educated people, such as the private cohort, are more likely to

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utilise customised wheelchairs and drive modified vehicles, which directly affects social and psychological outcomes post injury (Fyffe, Botticello and Myaskoysky, 2011).

5.4.4 Vocational factors

The private healthcare sector's patients were significantly better reintegrated into the working environment, with paid work, or a salary or wage. More of the private healthcare patients were predominantly self-employed, probably because they had better life skills and networks. Many of them did not have any financial constraints, therefore it was easier for them to start up their own business. The findings regarding the years of vocational training that the private patients had are aligned with why the private healthcare patients were able to integrate more efficiently into the workplace. It is as a result of the number of years of the vocational training that they received prior to their injury, which is higher than that of the cohort from the public healthcare sector. A study done in Taiwan shows that individuals that had sustained a TSCI after finishing high school had a 2.2-fold increased chance of returning back to work than those without it (Jang, Wang & Wang, 2005). This study also stresses the favourable factors for the reintegration, which is being able to utilise private and public transport independently, being married, being younger and those that had received vocational training post injury (Jang, Wang & Wang, 2005). These results correspond with the data from the private cohort.

Prior to sustaining a TSCI, the patients from the public healthcare sector depended mainly on their physical ability to provide financially for their family through manual labour (Burns and O'Connell, 2012). The public cohort struggled more to reintegrate into the work environment because of their lower educational levels before sustaining their injury compared to the private cohort (Øderud, 2014). No significant difference was found between the years of training post injury. Many of the private healthcare patients were able to

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reintegrate more easily into their work environment with minimal training as they were already settled in a career which allowed them to reintegrate more effectively.

The main reason why the private healthcare sector's patients could not find work was that the available work was not suitable. In the public cohort, however, their main reason was their health condition or disability. This reasoning is quite interesting to note, as both cohorts presented with similar conditions and disabilities, yet the private cohort gave a reason beyond their disability. It is noteworthy that the public cohort received more vocational training than the private cohort, yet they still gave the above-mentioned reason. It is interesting to note that a low-resourced country like Botswana reports to have a high rate of TSCI individuals returning to work as a result of follow up dates being prioritised by staff trained in SCI (Löfvenmark, Wikmar, Hasselberg, Norrbrink & Hultling, 2016).This gives the public cohort in Cape Town hope as with dedication and efficient planning, they can also attain higher return to work rates regardless of the lack of resources (Löfvenmark, Wikmar, Hasselberg, Norrbrink & Hultling, 2016).

It is evident from the aforementioned that the systems have a part to play in how cohorts are able to reintegrate and participate in society. Another reason for this is that financial hardship is directly proportional to a poorer functional ability and quality of life (Siegrist, Reinhardt, Brinkhof & Fekete, 2014).

5.5 SECONDARY COMPLICATIONS

Urinary tract infections, contractures, muscles spasm, pressure ulcers and autonomic dysreflexia were the main secondary complications experienced by the cohort from the public healthcare sector. This finding agrees with that of Øderud (2014). In the Netherlands, bladder and bowel regulations, pain, oedema, spasms and sexuality are the most struggled

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with secondary complications (Bloemen-Vrencken, Post, Hendriks, De Reus & De Witte, 2005). The fact that the Western Cape's public cohort only had access to two appropriate specialised units and one acute rehabilitation centre made it very difficult for these patients to make use of and be helped by these facilities, as patients were mostly seen based on priority (Joseph, 2016). Joseph et al. (2016) indicated that patients were discharged with no follow-up appointments, resulting in their being lost in the system and developing secondary complications, such as the above-mentioned, which could have been prevented. These results clearly indicate that the Western Cape's public health cohort undoubtedly needs a well-developed approach to the management of TSCI to be developed, regardless of the resource restraints and limited capacity. Research has shown that there is an association between socioeconomic status and the development of secondary complications, as TSCI patients suffer from more severe financial pressure as a result of their injuries (Siegrist, Reinhardt, Brinkhof & Fekete, 2014; Øderud, 2014). Pressure ulcers are common in low-resourced settings, such as the public cohort, as a result of poor nutrition and poor execution of pressure care regimes (Kruger, Pires, Ngann, Sterling, & Rubayi, 2013). Øderud mentions another valid justification to the presentation of pressure ulcers and infections, i.e. that rural settings with poor sanitation can easily lead to infection (2014). The three most predominant factors that the private healthcare sector's patients struggle with are sexual dysfunction, muscle spasm and sleeping problems. The muscle spasm can also justify why the private cohort is able to stand and sit with greater ease: according to Sezer, Akker and Uğurlu (2015), moderate to mild muscle spasm can assist with functional activities such as standing, transfers and ambulation. Sexual dysfunction, however, is a secondary complication that comes with the neurological deficit of sustaining a TSCI – there is nothing medical professionals can do to treat it (Schültke, 2006).

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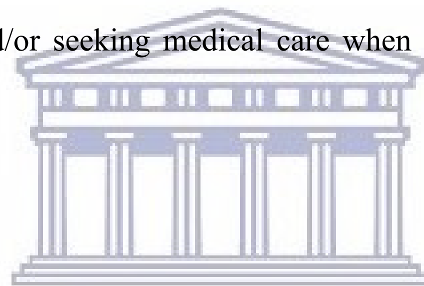
5.6 ENVIRONMENTAL FACTORS

5.6.1 Physical barriers

In the public cohort there was found to be a significant struggle with missing or insufficient accessibility of public places, missing or insufficient accessibility to homes of friends or relatives and unfavourable weather conditions. The findings of Burns and O'Connell (2012) align with this study's findings. Persons with TSCI living in a poor socioeconomic society are faced with the reality of having to move across harsh terrains with poorly adapted wheelchairs (Burns & O'Connell, 2012). The ability or otherwise to access public transport and the homes of their family members and friends indirectly affects their health. If they are not able to access public transport, they will experience profound challenges with getting to their clinic appointments, and/or seeking medical care when needed (Burns & O'Connell, 2012).



5.6.2 Attitudes

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Negative societal attitudes and negative attitudes of family and relatives were significantly higher in the public cohort than in the private cohort. Whereas there was no significant difference between the negative attitudes of friends, neighbours and colleagues, it could be that the private cohort was more educated and sensitised by staff.

5.6.3 Services and financial barriers

Lack of or insufficient nursing care and support services, insufficient medical and medical aid funds, problematic situations, lack of state services and insufficient communication devices were found to be significantly higher in the public cohort. The poor accessibility of

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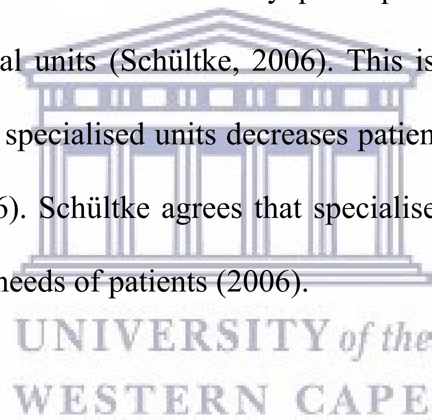
healthcare services as a result of harsh terrains makes accessing health care services a huge challenge (Øderud, 2014).

5.7 QUALITY OF LIFE

A significant difference was evident in the quality of lives of the two cohorts, the private cohort being superior. Good educational levels and financial status are significantly associated with an improved quality of life (Siegrist, Reinhardt, Brinkhof & Fekete, 2014), hence the private cohort had a significantly better quality of life compared to the public cohort. In the Balkan War (1912–1913), 80% of spinal cord injury patients never returned home, while the other 20% survived with a very poor quality of life as a result of no specialised spinal cord hospital units (Schültke, 2006). This is in line with what the study reflects. The lack of access to specialised units decreases patients' chances of having a good quality of life (Schültke, 2006). Schültke agrees that specialised units provide tailored care for the special and individual needs of patients (2006).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5.8 SUMMARY OF THE CHAPTER

It was found that in the private sector cohort there were more women that had sustained a TSCI than in the public sector. There is a significant difference in the aetiology of injury, with the private sectors main aetiology being traffic accidents and the public sector's being violence. These finding are in line with previous studies that indicate the main causes of TSCI in South Africa are gunshot wounds and traffic accidents. These results are also in line with international studies.

Preventative and education strategies should be in place to create awareness about TSCI. Improvements in and prioritising of pre-hospital care will play a crucial role in preventing

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the compromise of the integrity of the already damaged spinal cord. The private cohort was more independent than the pubic cohort in activities; their extensive and specialised rehabilitation was helpful in attaining these functional levels.

As a result of the public cohort only having access to two appropriate specialised units and one acute rehabilitation centre, it was difficult for patients to be helped by these facilities as patients are seen based on priority. Patients were lost in the system as they were discharged without any follow-ups or they struggled with getting to the healthcare centres. It was evident that the private cohort had a better quality of life than the public cohort. The lack of access to specialised units, financial status and levels of education appear to decrease patients' chances of leading a good quality of life, as well as reducing their financial status.

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CHAPTER 6: SUMMARY OF STUDY

6.1 INTRODUCTION

This chapter concludes the thesis. A summary of the study is presented, conclusions are made and the limitations, significance and recommendations are outlined.

6.2 SUMMARY OF STUDY

The aim of the study was to describe the health status and functioning of persons with TSCI in the Western Cape province who received public-funded care compared with those in the Gauteng province who received private care. The study was a cross-sectional comparison between two cohorts comprising a government-funded cohort in the Western Cape and private persons in Gauteng. This design provided a snapshot of the patient problems at one point in time without wanting to influence the study outcomes by applying an intervention.

The results indicated the following:

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The main cause of injury in the private cohort was traffic accidents (46.3%) and in the public cohort it was violence (47.3%). The private cohort has 70.73% of TSCI individuals that completed tertiary education compared to the 27.59% in the public cohort. The private cohort was also much more independent in activities. Of the private cohort, 2.5% had extreme problems with transportation compared with a 32.6% in the public cohort. Transport is one of the things that affects an individual's ability to participate in society. In the private cohort, the three most highly rated secondary complications in the "Severe problem" category were pain (34.1%), muscle spasm (29.3%) and urinary tract infection (24.4%).

There was no statistical difference between handling stress, using hands, intimate relationships, doing things for pleasure, siting unsupported, getting up from the floor and

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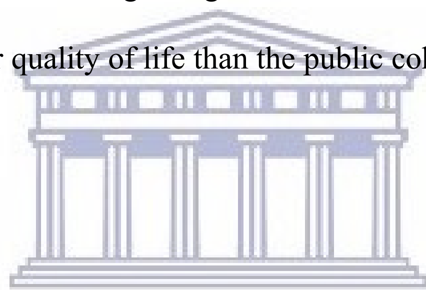
moving from the side of the bed to lying on one's back. These aspects do not require money to improve, they are solely affected by the completeness of the injury and the level of injury. Twenty-two per cent of the private cohort were self-employed and 48.8% of the private cohort earned a salary or wage. In the public cohort, the three most prevalent secondary complications were muscle spasm (20.2), pain (20.2) and circulatory problems (11.6). All the environmental restrictions that made participants' lives more difficult were those things that required money to access. These affected the public cohort significantly more than the private cohort.

The private cohort rated the quality of life option more frequently (35.7%) compared to the public cohort, (6.7%), with there being a significant difference (p= 0.0001). The private cohort reported having a better quality of life than the public cohort.



6.3 LIMITATIONS

There were certain limitations to the study, as indicated below.

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- Representativeness: Owing to the convenient sampling method used, the findings cannot be generalised to the entire population of persons with TSCI in South Africa.
- External validity: As a result of the sample size, the private cohort having 41 participants and the public cohort being more than double the amount (97 participants), the results need to be interpreted with caution.
- The study was cross-sectional in nature. Causality between the healthcare plan and functioning cannot be inferred. Not all the participants answered all the questions, possibly because their "answer" was not part of the list of options provided. There was a degree of selection bias, as some individuals may not have had access to a telephone/email, and were, therefore, excluded from the study.

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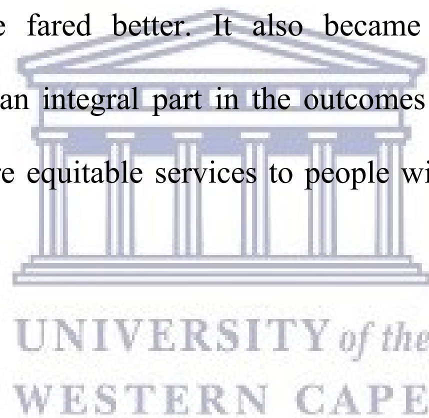
- Only self-reported measures were used. In such an approach, there is a risk that survivors either over- or underestimate their health problems and functioning. More objective measures of functioning should be used in the future.

6.4 SIGNIFICANCE OF THE STUDY

The significance of this work lies in the assessment of different healthcare systems for people with TSCI in South Africa. By contrasting these two systems, it was possible to learn the benefits and disadvantages of each.

Discrepancies were found in health status and functioning between the systems, indicating that those with private care fared better. It also became evident that education and socioeconomic position play an integral part in the outcomes post TSCI. This information could be used to provide more equitable services to people with TSCI in the public-funded sector.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6.5 RECOMMENDATIONS

It would be valuable if the financial effects of a TSCI on a family could be explored in future studies. It is recommended that a more representative sample of persons with TSCI should be included in order to inform policy changes, as there was quite a huge difference in the sample size between the two cohorts. Longitudinal studies should be performed with multiple assessment points in order to assess causality to determine whether the healthcare plan influences health status and functioning.

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6.5.1 Recommendation for the Western Cape Department of Health

It is recommended that more policies be developed and implemented by the Western Cape Department of Health to prevent the secondary complications indicated in this study. Education on the prevention of secondary complications should be prioritised. A multi-disciplinary approach to treating TSCI should be enforced while treating patients with specialised care. It would be beneficial if systems could be put in place to improve pre-hospital care management of patients with SCI in order to improve patient quality of life and prognosis. Lastly, it is suggested that the Western Cape Department of Health should invest in medical care that would make provision for accurate diagnosis of SCI and for treating patients by way of a specialised approach. It is imperative that prevention strategies be implemented and enforced to prevent the occurrence of TSCI. It is evident that the public health sector of the Western Capes needs a well-developed approach to the management of TSCI, regardless of the resource restraints and limited capacity.

6.5.2 Recommendation for the private healthcare system

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It would be interesting to explore in future research how those individuals that have sustained TSCI and that have medical aid and access to the private care system integrate back into society if they do not come from a wealthy background.

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CHAPTER 7: REFERENCES

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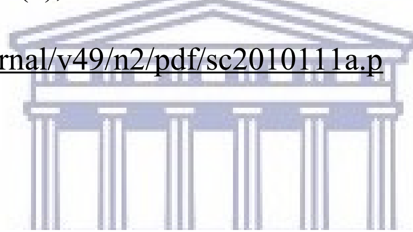

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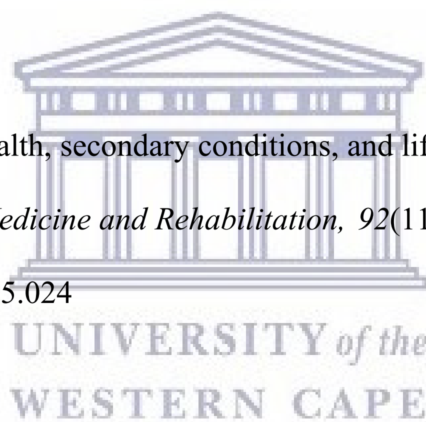
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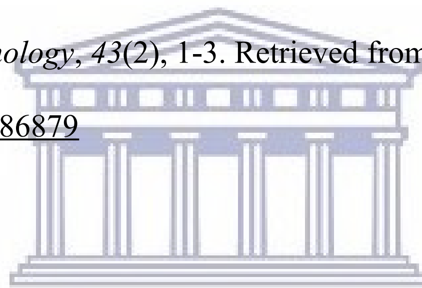

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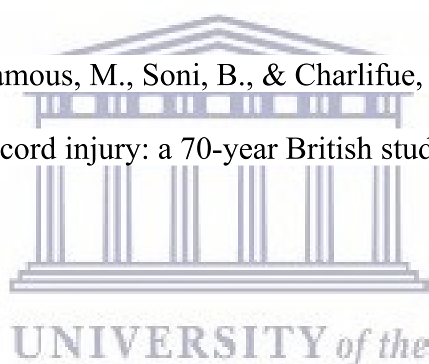

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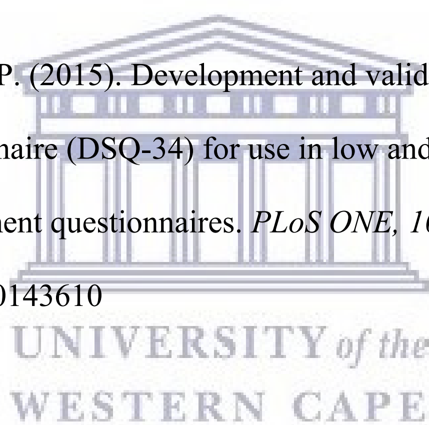
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APPENDICES

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Appendix 2

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Tel: +27 21-959 2542 Faks: 27 21-959 1217
E-pos: jefthatarryn@gmail.com

INLIGTINGSBLAD

Projek Titel: Gesondheid status en funksionering na 'n traumatiese spinaal koord besering in Suid Afrika. Dit is 'n vergelyking tussen privaat en publieke gesondheidsorg befondse kohort.

Wat behels hierdie studie?

Dit is 'n navorsingsprojek wat deur Tarryn Kim Jeftha van die Universiteit van die Wes-Kaap gedoen is. Hierdie studie ondersoek aktiwiteit beperkings en deelname beperkings van pasiënte na traumatiese spinaalkoord beserings. Die belangrikste motief om te bepaal is wat u beperkinge binne die gemeenskap ná beserings is en voorstel hoe die gesondheid stelsel verbeter kan word.

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

U sal gevra word om 'n sessie met 'n narvorser op 'n plek wat gemak is vir jouby te woon. U sal vrae in verband met u besering, funksionele vermoens en welstand beantwoord. Dit sal in een sessie gedoen word en die sessie sal omtrent 30-45 minute lank wees.

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Sal my deelname in hierdie studie vertroulik gehou word?

U persoonlike inligting sal ten alle tye konfidensieel gehou word. Ek sal geen persoonlike informasie in die vraelys voeg nie. Alle vertroulike inligting wat ingesaamel word sal ten alle tye in 'n liasseringskas bewaar word. Om U vertroulikheid te beskerm sal geen ongemagtigde partye toegang het tot u inligting nie. Jou identiteit sal met die grootste mate moontlik beskerm word in die geval dat 'n verslag of artikel geskryf word.

'n Ooreenstemming met wetlike vereistes en/of professionele standaarde, sal ons die toepaslike individue en/of owerhede inlig in verband met kindermishandeling of verwaarlosing of potensiële skade aan jou of anders. Risikos sal deur informele toestemming versag word, ons sal geen konfidensieele en sensitiewe inligting oortree nie. Met die gebruik van prosedure waarmeer narvosing konstant is, sal deelnemers geen risikos blootgestel word nie. As u op enige manier getraumatiseer is, sal U daarna verwys word.

Wat is die risikos van hierdie navorsing?

Daar is geen bekende risikos verbonde aan deelname aan hierdie navorsingsprojek.

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Appendix 2

Wat is die voordele van hierdie navorsing?

Op ’n persoonlike vlak sal jy meer ingelig word oor hoe die besering you raak. Jy sal ook ingelig word oor hoe jy met jou besering teen ander mense met die selfde besering vorder.
Op 'n breër perspektief, kan hierdie inligting van gesondheid stelsels vir persone met traumatiese spinaalkoord beserings in Suid-Afrika versterk work.

Is ek verplig om in hierdie navorsing deel te neem en ek kan op enige tydstip onttrek?

U deelname in hierdie navorsing is heeltemal vrywillig. Dit is U keuse om deel te neem of nie. As jy besluit om in hierdie navorsings projek deel te neem, kan jy op enige tyd ontrek. Indien u besluit om nie deel te neem aan hierdie studie nie, en as u ophou deel te neem op enige tyd, sal u nie gepenaliseer word of enige voordele verloor wat jy andersins voor kwalifiseer nie.

Wat gebeur of ek vrae het?

Die navorsing is deur Vania Van Wyk by die Universiteit van die Wes-Kaap gedoen. As jy enige vrae het oor die navorsing, kontak my asseblief op 0719462836 of e-pos
jefthatarryn@gmail.com

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Indien jy nog enige vrae met betrekking tot hierdie studie en jou regte as 'n navorsings deelnemer of as jy enige probleme wil rapporteer wat jy ervaar het met betrekking tot die studie, kontak asseblief: Dr Conran Joseph (Toesighouer) by die Universiteit van die Wes-Kaap op
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epos: cjoseph@uwc.ac.za

Hoof van Departement: Dr Nondwe Mlenzana: nmlenzana@uwc.ac.za
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Dekaan van die Fakulteit van gemeenskap en Gesondheidswetenskappe:
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Appendix 2

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Appendix 1

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INFORMATION SHEET FOR PARTICIPANTS

Project Title:
HEALTH STATUS AND FUNCTIONING AFTER TRAUMATIC SPINAL CORD INJURY IN SOUTH AFRICA: COMPARISON BETWEEN A PRIVATE AND PUBLIC HEALTH CARE FUNDED COHORT

What is this study about?

This is a research project being conducted by the Spinal Cord Injury (SCI) Research Group at the University of the Western Cape. This is a multi-continent study investigating societal response to persons living with an SCI. The main motive is to determine your health and wellness needs and to propose how the health system could be improved.

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

You will be asked to attend a session with one of the researchers and answer questions related to your injury, functional capabilities, and wellness. This will be done only on one occasion. The session will last approximately 40 minutes.

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Would my participation in this study be kept confidential?

I will do my best to keep your personal information confidential, by not adding your personal information on the questionnaire. 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. In the event of writing a report or article, your identity will be protected to the greatest extent possible, by not using your name.

In accordance with legal requirements and/or professional standards, I will disclose to the appropriate individuals and/or authorities information that comes to our attention concerning child abuse or neglect or potential harm to you or others. Risks will be mitigated by providing inform consent, not breeching confidentiality of sensitive information, using procedures that are constant with research that does not expose participants to risks. If you are traumatised in any way, you will be referred accordingly.

What are the risks of this research?

There are only minimal risks associated with participating in this research project. All precautions will be taken to prevent any negative emotional responses. This study does not pose any direct negative consequences to participants. However, there are minimum risks in the form of

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sensitivity, by reflecting on their health status and functioning. I will provide them with information about the process of seeking psychological care.

What are the benefits of this research?

On a personal level, you will gain an understanding of how the injury affected you and how you function in relation to others with similar injuries. From a broader perspective, 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.

What if I have questions?

This research is being conducted by Tarryn Jeftha at the University of the Western Cape. If you have any questions about the research study itself, please contact me at: work number 021-959 3662 or cell: 071 9462 836, e-mail 3363790@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:
Head of Department: Dr Nondwe Mlenzana; nmlenzana@uwc.ac.za

Dean of the Faculty of Community and Health Sciences: Prof Anthea Rhoda arhoda@uwc.ac.za
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Appendix 3

IDyunivesiti YELASE Ntshona Koloni

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E-mail: jethatarryn@gmail.com

Sheet Ulwazi

Isihloko soPhando lweProjekthi:

Uphando lwempatho nobumi emva kokonzakala umnqonqo. Uthelekiso Phakathi kwecandelo labucala necandelo likeRhulumente.

Lungantoni oluphando phezulu?

Oluphando nzulu iwenziwe ngu Vania van Wyk ongumfundi kwiDyuvesi yelase Ntshona koloni. Le yintlanganisela yezifundo zophando zempendulo yengqungquthela kumntu ophila ne SCI. Injongo ephambili kukuchaza ngempilo kwakunye nezidingo zokuphila kwakupapasha ukuba ingaphucula njani inlela yokuphila.

Ndizocelwa ukuba ndenze ntoni ndakuba ndivumile ukuba yinxalenye?

Uzakucelwa ukuba ungene imihlangano kunye nomnye wabaphandi uphendule imibuzo malunga nokulimala kwakho, nokusebenza onako kunye nempilo yakho. Lento izokwenziwa ngamaxesha athile, izakuthatha imizuzu engama 30 ukuya kwimizuzu engama 45.

Ingaba inxaxheba yam koluphando izakugcinwa iyimjihlelo na?

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ndizokwenza konke okusemendleni ukugcinca inkcukacha zakho zibe yimfihlo. Ukunceda ukhuseleko, zonke inkcukacha ezigokeleewayo zizakubekwa kwindawo ekhuselekileyo efihlakeleyo. Akukho bantu bangavumelekanga abazokuyifumana. Kumbe wobhalelwano, nokukhushwa kwamaphepha, akuzokubhalwa ngama lakho Ukhuseleko luzoba kwingqanaba eliphezulu.
Mayelama nezinto zomthetho, nezigaba zokufunda, sizokubenise abantu abalilungelo,
nebasemagunyeni okwazi inkcukacha ezo ezimalunge nokuxhatshazwa kwabanttwana, ukungahoywa kunye nokuvisa kabuhlungu wena nabanye abantu.

Buyintoni obunzozi boluphando?

Ngokumalunge nawe, uzokufumana ulwezi ngokuba ukulimala kukuchaphazela njani, okunye
usebenza njani xa ujonga nabanye abalimelengokufana nawe. Ulwazi olubenzi, olulwazi lunga kunceda ukuqinise ukomeleza kubantu abaneTSCI eMazantsi Afrika.

Kuyanyananzeleka ukuba ndibe koluphando okanye ndingayyeka nangaliphi ixesha ndifuna?

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Appendix 3

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Appendix 5

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CONSENT FORM

Title of Research Project: **Health status and functioning after a traumatic spinal cord injury in South Africa. It is a comparison study between a private and a public funded cohort.**

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

Participant's name……………………….

Participant's signature……………………………….

Date………………………

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Robert Sobukwe Road
Bellville
Cape Town

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Appendix 5

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research-ethics@uwc.ac.za

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Appendix 6

Universiteit VAN DIE WES Kaap

Privaat Sak: X 17, Bellville 7535, Suid Afrika
Tel: +27 21-959 2542
Faks: 27 21-959 1217
E-pos: jefthatarryn@gmail.com

Toestemmingsvorm

Die studie was aan my in 'n taal wat ek verstaan beskryf gewees. My vrae oor die studie was beantwoord. Ek verstaan wat my deelname behels en ek stem saam om van my eie keuse en vrye wil deel te neem. Ek verstaan dat my identiteit sal nie openbaar aan enigeiemand gemaak word nie. Ek verstaan dat ek uit die studie enige tyd kan uittrek, sonder rede gee en sonder van negatiewe gevolge of verlies van voordele vrees.

Naam van deelneemer:

Deelneemer se handtekening:

Datum:

BMREC
Robert Sobukwe Road
Bellville
Kaapstad
7535
Tel: +2721 959 4111
research-ethics@uwc.ac.za

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Appendix 7

IDyunivesiti YASE Ntshona Koloni

Ibhokisi ebucala X 17, Bellville 7535, Mzantsi Afrika
Nombola: +27 21-959 2542, Fekisi: 27 21-959 1217
E-mail: jefthatarryn@gmail.com

Ifomu Yomsebenzi

Isihloko soPhando lweProjekthi:
Uphando lwempatho nobumi emva kokonzakala umnqonqo. Uthelekiso Phakathi kwecandelo labucala necandelo likaRhulumente.
Isifundo siye sacaciswa kum ngolwimi endiluqondayo. Imibuzo yam malunga nesifufundo iphendulwe. Ndiyayiqonda ukuba inxaxheba yam iyakubandakanya ntoni na kwaye ndiyavuma ukuthatha inxaxheba ngokuzikhethela kwanokukhululeka. Ndiyaqonda ukuba ubumna abusoze baziswa nakubani na. Ndiyaqonda
ukuba ndinako ukurhoxisa izifundo nanini na kwesi sifundo ngaphandle kokunika isizathu nangaphandle kokoyika nemiphumela emibi okanye ukulahleka kwezibonelelo.

Igama lomthathinxaxheba :
Isinyatheliso somthathi nxaxheba :
Umhla :

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Appendix 8

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International Spinal Cord Injury Survey (InSCI)

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.

A collaboration of

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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]. 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 (InSCIID) and there is no personal information such as name or address on the paper or online questionnaire.

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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 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?

....

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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

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- ☐ Friends
- ☐ Professionals or paid assistants

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

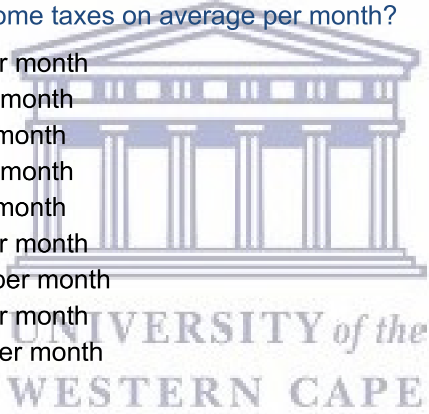
- ○ Primary
- ○ Lower secondary
- ○ Higher secondary
- ○ Post-secondary
- ○ Short tertiary
- ○ Bachelor or equivalent
- ○ Master or equivalent
- ○ Other, namely: ……………………………………………………

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?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- ○ 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***

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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 (<u>unable to feel and move</u> any part of your body below injury level)
- Incomplete (<u>able to feel or move</u> 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*

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- ☐ 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.

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

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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?
24. Sleep problems *e.g., problems falling asleep or sleeping through the night and waking up early.*						○ Yes ○ No
25. Bowel dysfunction *e.g., diarrhea, stool incontinence ('accidents') and constipation.*						○ Yes ○ No
26. Urinary tract infections *e.g., kidney or bladder infection.*						○ Yes ○ No
27. Bladder dysfunction *e.g., incontinence ('accidents'), bladder or kidney stones, kidney problems, urine leakage and urine back up.*						○ Yes ○ No
28. Sexual dysfunction *e.g., difficulty with sexual arousal, erection, lubrication, and reaching orgasm.*						○ Yes ○ No
29. Contractures *This is a limitation in the range of motion of a joint.*						○ Yes ○ No
30. Muscle spasms, spasticity *This refers to uncontrolled, jerky muscle movements, such as uncontrolled muscle twitches or spasms.*						○ Yes ○ No
31. Pressure sores, decubitus *These develop as a skin rash or redness and may progress to an infected sore.*						○ Yes ○ No
32. Respiratory problems *Symptoms of respiratory infections or problems include difficulty in breathing and increased secretions.*						○ Yes ○ No
33. Injury caused by loss of sensation *e.g., burns from carrying hot liquids in the lap or sitting too*						○ Yes ○ No

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	close to a heater or fire.						
34.	**Circulatory problems** *This involves the swelling of veins, feet, legs or hands, or the occurrence of blood clots.*						○ Yes ○ No
		1 *No problem*	*2*	*3*	*4*	*5* *Extreme problem*	*Do/did you receive treatment for it?*
35.	**Autonomic dysreflexia** *Symptoms are sudden rises in blood pressure and sweating, skin blotches, goose bumps, pupil dilation and headache.*						○ Yes ○ No
36.	**Postural hypotension** *This involves a strong sensation of lightheadedness following a change in position. It is caused by a sudden drop in blood pressure.*						○ Yes ○ No
37.	**Pain** *Having pain in your day-to-day life.*						○ Yes ○ No

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

No pain *you can imagine*

○ 0 1 2 3 4 5 6 7 8 9 10

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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

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○ Former smoker
○ Current smoker (including occasional smoker)

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

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periods such as 30 minutes?

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…	*Without any difficulty*	*With a little difficulty*	*With some difficulty*	*With much difficult y*	*Unable to do*
56.	**…get up off the floor from lying on your back?**	⊥H	⊥H	⊥H	⊥H	⊥H
57.	**…push open a heavy door?**	⊥H	⊥H	⊥H	⊥H	⊥H
58.	**…moving from sitting at the side of the bed to lying down on your back?**	⊥H	⊥H	⊥H	⊥H	⊥H

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Independence in activities of daily living

For each item, please check the box next to the statement that best reflects <u>your current situation.</u> 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 <u>upper body and head</u>

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 <u>lower body</u>

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, chai*
- ○ I am independent and do not need adaptive devices or specific equipment

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62. Dressing your <u>upper body</u>

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

- *<u>Easy-to-dress</u> clothes are those <u>without</u> buttons, zippers or laces*
- *<u>Difficult-to-dress</u> clothes are those <u>with</u> 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 <u>lower body</u>

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

- *<u>Easy-to-dress</u> clothes are those <u>without</u> buttons, zippers or laces*

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- *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

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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

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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 in a chair or wheelchair
- ☐ None, I need assistance in all these activities

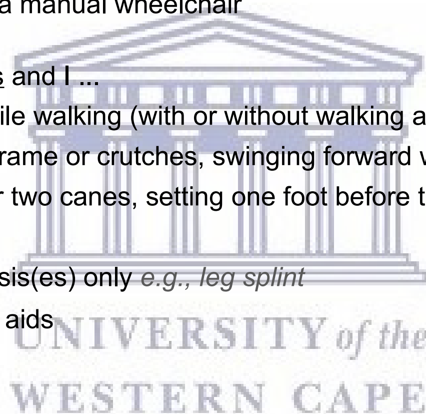
69. Transfers from the bed to the wheelchair

- ○ 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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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

Work

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?

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- ○ 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?

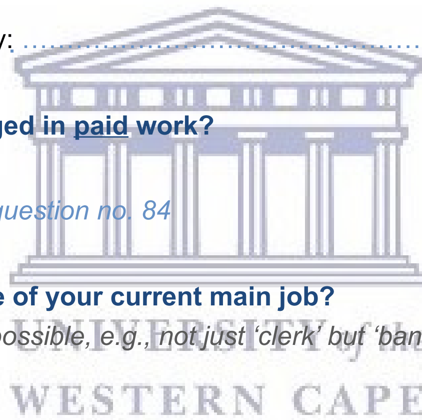
- ○ Yes
- ○ No

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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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 No problem	*2*	*3*	*4*	*5 Extreme problem*
79. How much of a problem is getting things done as required at work?	☐	☐	☐	☐	☐
80. How much of a problem do you have in accessing your workplace? *e.g., access to the building, your office or toilets*	☐	☐	☐	☐	☐

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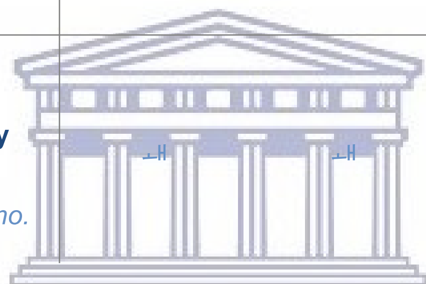
	Completely	To a large extent	To some extent	To a small extent	Not at all	I do not have such a need
81. Do you have the assistive devices that you need for work? *e.g., assistive computer devices, adjustable desks or arm/hand braces or prosthetics*	⊥H	⊥H	⊥H	⊥H	⊥H	⊥H

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.

	Strongly agree	Agree	Disagree	Strongly disagree
82. I receive the recognition I deserve for my work.	⊥H	⊥H	⊥H	⊥H
83. Considering all my efforts and achievements, my salary is adequate. *Please go to question no. 87*	⊥H	⊥H	⊥H	⊥H



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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

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- ☐ 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.	**Missing or insufficient accessibility of public places** *e.g., inaccessible public buildings, parks*				
88.	**Missing or insufficient accessibility to the homes of friends and relatives**				
89.	**Unfavorable climatic conditions** *e.g., weather, season, temperature, humidity*				
90.	**Negative societal attitudes toward persons with disability** *e.g., prejudice, stigma, ignorance*				
91.	**Negative attitudes of your family and relatives with regards to your disability** *e.g., prejudice, lack of support, overprotective behavior*				
92.	**Negative attitudes of your friends with regards to your disability** *e.g., prejudice, lack of support, overprotective behavior*				
93.	**Negative attitudes of neighbors, acquaintances and work colleagues with regards to your disability** *e.g., prejudice, lack of support, overprotective behavior*				
94.	**Lack of or insufficient adapted assistive technology for moving around over short distances** *e.g., stair lift, walking aids or wheelchair*				
95.	**Lack of or inadequate adapted means of transportation for long distances** *e.g., lack of adapted car or hard to use public transportation*				
96.	**Lack of or insufficient nursing care and support services** *e.g., home health care or personal assistance*				
97.	**Lack of or insufficient medication and medical aids and supplies** *e.g., catheters, disinfectants, splints, pillows*				
98.	**Problematic financial situation** *e.g., shortage of money*				
99.	**Lack of or insufficient communication devices** *e.g., lack of or insufficient writing devices,*				

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	computer, telephone, mouse				
100.	**Lack of or insufficient state services** *e.g., disability insurance or other benefits*				

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?

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.... *(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?**					
104.	**…how clearly health care providers explained things to you?**					
105.	**…your experience of being involved in making decisions for your treatment?**					

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

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- ☐ 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:

. ...

	Very satisfied	*Satisfied*	*Neither satisfied nor dissatisfied*	*Dissatisfied*	*Very dissatisfie d*
107. In general, how satisfied are you with how the health care services are run in your area?	☐	☐	☐	☐	☐

Personal factors

The following questions are about how you see yourself.

	1 Not at all	*2*	*3*	*4*	*5 Completel y*
108. How confident are you that you can find the means and ways to get what you want if someone opposes you?	☐	☐	☐	☐	☐
109. How confident are you that you could deal efficiently with unexpected events?	☐	☐	☐	☐	☐
110. How confident are you that you can maintain contact with people who are important to you?	☐	☐	☐	☐	☐
111. How confident are you that you can maintain good health?	☐	☐	☐	☐	☐
112. Do you think that living with your spinal cord injury has made you a stronger person?	☐	☐	☐	☐	☐
113. Do you worry about what might happen to you in the future? *e.g., thinking about not being able to look after yourself, or being a burden to others in the future*	☐	☐	☐	☐	☐

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114. Do you feel that you will be able to achieve your dreams, hopes, and wishes?					
115. Do you get to make the big decisions in your life? *e.g., deciding where to live, or who to live with, how to spend your money*					
116. Do you feel included when you are with other people?					

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 last 14 days…	*Very poor*	*Poor*	*Neither poor nor good*	*Good*	*Very good*
118. How would you rate your quality of life?					

	Very dissatisfied	*Dissatisfied*	*Neither satisfied nor dissatisfied*	*Satisfied*	*Very satisfied*
119. How satisfied are you with your health?					
120. How satisfied are you with your ability to perform your daily living activities?					
121. How satisfied are you with yourself?					
122. How satisfied are you with your personal relationships?					
123. How satisfied are you with your living conditions?					

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

- ○ Excellent
- ○ Very good
- ○ Good
- ○ Fair

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- ○ 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

We thank you very much for participating in the InSCI survey!

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Appendix 9

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International Spinal Cord Injury Survey (InSCI)

Afrikaanse weergawe

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

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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.

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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]. 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 standaarde. 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.

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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 of skakel ons tolvry InSCI-helplyn by 021 959 2542.

Weereens dankie vir u verbintenis!

U InSCI-Span

Dr Conran Joseph

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?

- ○ Enkellopend
- ○ 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

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- ☐ 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.

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Besering eienskappe

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: ………………………………………..……………

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Oorsaak a.g.v. siekte:

Merk als wat van toepassing is

- ☐ Degenerasie van die spinalekolom
- ☐ Gewas - Goedaardig
- ☐ Gewas – kwaadaardig (kanker)
- ☐ Vaskulêre problem (bv.bloedloosheid, bloedvloeiing, 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

ㅈ ㅈ /ㅈ ㅈ /ㅈ ㅈ ㅈ ㅈ

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.

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

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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?*
24. Slaapprobleme Bv.*Dit sluit in problem om aan die slaap te raak, om deurnag te slaap en om vroeg wakker te raak..*						○ Ja ○ Nee
25. Probleme met ontlasting Bv. *Dit sluit in diarree,stoelgang onbeheerstheid (ongelukke) en konstipasie.*						Ja Nee
26. Urinekanaalinfeksie *Bv.Dit sluit in nier- en blaasinfeksies.*						Ja Nee
27. Blaasdisfunksie Bv.*Dit sluit in swak van blaas of nierstene, urinelekkasie, terugtrek van urine.*						Ja Nee
28. Seksuele disfunksie *Bv. Dit sluit in disfunksie in seksuele opwekking, ereksie en bereiking van orgasme.*						Ja Nee
29. Kontrakture *Dit is die limitasie (tekortkoming) rakende die reikwydte van die beweging van spiere.*						Ja Nee
30. Spiersametrekkings, spastisiteit *Dit verwys na onbeheerste, rukkerige spierbewegings, soos bv. onbeheerste spiertrekkings en krampe.*						Ja Nee
31. Druksere ,Bedsere *Hierdie ontwikkel as 'n veluitslag of rooiheid van die vel en ontwikkel verder as 'n geïnfekteerde seer.*						Ja Nee
32. Respiratoriese Probleme (Asemhalingsprobleme) *Simptome van respiratoriese infeksies of – probleme sluit in moeilikheid met asemhaling en toenemende uitskeidings.*						Ja Nee

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33. Beserings veroorsaak deur die gebrek aan sensasie *Bv. Dit sluit in brandwonde opgedoen deur warm vloeistof in die skoot te dra of deur te na aan die vuur of die verwarmer te sit.*	☐	☐	☐	☐	☐	☐ Ja ☐ Nee
34. Sirkulasieprobleme *Dit sluit in geswelde are van voete, bene en hande, of die ontwikkeling van bloedklonte.*	☐	☐	☐	☐	☐	○ Ja ○ Nee
	1 Geen probleem	*2*	*3*	*4*	*5 Uiterste probleem*	*Het u behandeling daarvoor gekry?*
35. Outonomiese disrefleksia *Simptome is skielike styging in bloeddruk en sweet, vlekke of puisies op die vel, pupiluitsetting en hoofpyn.*	☐	☐	☐	☐	☐	○ Ja ○ Nee
36. Posturale lae bloeddruk *Dit veroorsaak 'n sterk sensasie van lighoofdigheid na 'n verandering van posisie as gevolg van 'n skielike daling in die bloeddruk.*	☐	☐	☐	☐	☐	○ Ja ○ Nee
37. Pyn *Om pyn in jou daaglikse lewe te ondervind*	☐	☐	☐	☐	☐	☐ Ja ☐ Nee

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

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

☐ Geen addisionele gesondheidsprobleme om te verklaar

. ...

. ...

. ...

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. ...

. ...

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 Geen probleem*	*2*	*3*	*4*	*5 Uiterste probleem*
41.	… daaglikse roetine uit te voer?					
42.	… stress te hanteer?					
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?					
44.	… te kom waar u wil wees?					
45.	… publieke vervoer te gebruik?					
46.	… privaate vervoer te gebruik?					
47.	… na u gesondheid om te sien, gesond te eet, oefen of u medikasie te neem?					
48.	… u huishoudelike take klaar te maak?					
49.	… ander te versorg en van hulp te wees?					
50.	… met ander te interakteer?					
51.	… met intieme verhoudings?					
52.	… dinge vir ontspanning of plesier te doen?					
53.	… word u kort van asem gedurende fisieke inspanning?					
54.	Is u in staat om te ongesteund te					

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sit? ○ Nee ○ Ja → Hoeveel van 'n probleem is dit om vir lang periodes soos 30 minute te sit?	
55. Is u in staat om ongesteund te staan? ○ Nee ○ Ja → Hoeveel van 'n probleem is dit om vir lang periodes soos 30 minute te staan?	

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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. verplasinsplank, hyskraan, hospitaalbed.

	Is u in staat om…	*Geen moeilikheid*	*Kleine moeilikheid*	*Met sommige moelikheid*	*Met baie moeilikheid*	*Nie in staat om uitevoer nie*
56.	… vanaf 'n posisie waar u op u rug lê, sonder hulp op te staan?	☐	☐	☐	☐	☐
57.	…'n swaar deur oop te stoot?	☐	☐	☐	☐	☐
58.	… vanaf 'n sittende posisie op die kant van die bed te verskuif deur op u rug te gaan lê?	☐	☐	☐	☐	☐

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Onafhanklikheid van aktiwiteite van die daaglikse lewe

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

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

- O Ek benodig totale bystand.
- O Ek benodig gedeeltelike bystand.
- O 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.

- O Ek benodig totale bystand.
- O Ek benodig gedeeltelike bystand.
- O 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*

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

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63. Klee van die <u>onder gedeelte</u> 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

- *<u>Maklik- om – aan- te- trek</u> klere is klere <u>sonder</u> knope, ritssluiters en veters*
- *<u>Moeilik- om- aan- te- trek</u> klere is klere <u>met</u> knope, ritssluiters en veters*

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

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

65. Blaashantering

Dink asseblief aan die manier hoe u u blaas verlig.

A. Gebruik van 'n interne kateter

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

B. Onderbroke katetergebruik

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

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

O Ek benodig algehele bystand
O Ek benodig gedeeltelike bystand
O Ek gebruik dit sonder bystand
O 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)***?**

O Ja
O Nee

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B.Ek ontlas…

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

C.Ontlastingsonbeheerstheid (ongelukkies) vind plaas …..

- ○ Daagliks
- ○ 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

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- ○ 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 aktiwitete kan u sonder hulp of elektroniese apparate 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.

Werk

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. beroepsvoorligting, beroepsheropleiding,werkvaardigheidsopleiding

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- ○ 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.
- ☐ Selfindiensname, 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:

....

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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
- ○ Dieselfde aantal ure

	1 Geen probleem	2	3	4	5 Uiterse probleem
79. Hoeveel van 'n probleem is dit om dit wat van u by die werk verwag word, gedaan te kry?					
80. Hoeveel van 'n probleem is dit om toegang tot u					

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werkplek te verkry? *bv. toegang tot die gebou, u kantoor of die toilette*	

	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? *bv. hulpverleningsrekenaarapparate, arm- of handstutte of kunsmatige ledemate.*	⊥H	⊥H	⊥H	⊥H	⊥H	⊥H

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.	⊥H	⊥H	⊥H	⊥H
83. Al my harde werk en prestasies in ag geneem, is my vergoeding billik. ▭ *gaan asseblief na vraag 87*	⊥H	⊥H	⊥H	⊥H

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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

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☐ Besig met opvoedings- en werksopleiding
☐ Persoonlike familieverantwoordelikheid
☐ 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, gesondheidsversekerigsdekking* ⎵ 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 toepassi g	Geen invloed	Maak my lewe tot n mate moeilik	Maak my lewe baie moeilik
87. Afwesigheid of onvoldoende toeganklikheid tot openbare plekke *bv. ontoeganklike publieke geboue,parke*				
88. Afwesigheid of onvoldoende toegang tot vriende en familie se huise.				
89. Swak klimaatstoestande *bv. weer,seisoen,temperatuur,humiditeit*				
90. Negatiewe gesindhede van die gemeenskap teenoor gestremde persone *bv. vooroordeel, stigma, onkunde*				
91. Negatiewe gesindhede van u gesin an ander familie teenoor u gestremdheid *bv. vooroordeel, gebrek aan ondersteuning, oorbeskerming*				
92. Negatiewe gesindhede van u vriende teenoor u gestremdheid *bv. vooroordeel, gebrek aan ondersteuning, oorbeskerming*				
93. Negatiewe gesindhede van u bure, kennisse en kollegas teenoor u gestremdheid *vooroordeel, gebrek aan ondersteuning, oorbeskerming*				
94. Gebrek aan- of onvoldoende ondersteuningstegnologie om oor kort afstande te beweeg *gebrek aan- of onvoldoende hulp om trappe te klim, loop apparate, rolstoel*				
95. Gebrek aan of onvoldoende aanpassing van vervoer oor lang afstande *bv. tekort aan aangepaste motor, publieke vervoer wat moeilik gebruik word.*				
96. Tekort aan of onvoldoende verpleegsorg en ondersteunende dienste *bv. tekort aan of onvoldoende gesondheidssorg by die huis of persoonlike hulp*				

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97.	**Gebrek aan of onvoldoende medikasie en mediese bystand en -voorrade** *bv. gebrek aan of onvoldoende kateters, ontsmettingsmiddels,spalke,kussings*				
98.	**Moeilike finansiële posisie** *bv. tekort aan geld*				
99.	**Gebrek aan- of tekort aan kommunikasieapparate** *bv. gebrek aan of onvoldoende skryfapparate,rekenaar,telefoon, muis*				
100.	**Gebrek aan of onvoldoende staatsdienste** *bv. gebrek aan of onvoldoende ongeskiktheidsversekering of ander voordele*				

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 gesondheidssorgvoorsiener 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 gesondheidssorgvoorsiener?	*Baie goed*	*Goed*	*Nie goed of swak nie*	*Swak*	*Baie swak*
103.	**...u ervaring om met respek behandel te word.**					
104.	**…hoe duidelik die gesondheidssorgvoorsieners**					

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dinge verduidelik.					
105. … u ervaring van u betrokkenheid in die besluite wat geneem word rakende u behandeling.	⊔	⊔	⊔	⊔	⊔

106. In die afgelope 12 maande, het u gesondheidssorg benodig, maar dit nie ontvang nie?

- ○ Nee
- ○ Ja. Watter redes verduidelik ten beste waarom u nie die gesondheidssorg 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 gesondheidssorgvoorsiener het 'n tekort aan geneesmiddels en toerusting gehad.
- ☐ Die gesondheidssorgvoorsiener se vaardighede was ontoereikend.
- ☐ Ek het nie geweet waarheen om te gaan nie.
- ☐ Ek het probeer, maar is gesondheidssorg geweier.
- ☐ Ek het gedink dat ek nie siek genoeg was nie.
- ☐ Ander, spesifiseer asseblief

. ……………………………………………………………………………

	Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied
107. In die algemeen, hoe tevrede is u met die gesondheidssorgdienste in u area?	⊔	⊔	⊔	⊔	⊔

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Persoonlike faktore

Die volgende vrae handel oor hoe u uself sien.

	1 Glad nie	2	3	4	5 Ten volle
108. In hoe 'n mate is u seker dat u oor die vermoë beskik om u sin te kry as iemand u sou teenstaan?	⊔	⊔	⊔	⊔	⊔
109. Hoe seker is u dat u in staat is om onverwagte gebeurlikhede effektief te kan hanteer?	⊔	⊔	⊔	⊔	⊔

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110. **Hoe seker is u dat u kontak sal kan behou met die mense wat vir u belangrik is?**	☐	☐	☐	☐	☐
111. **Hoe seker is u dat u goeie gesondheid kan handhaaf?**	☐	☐	☐	☐	☐
112. **Dink jy dat jou spinale koordbesering u 'n sterker persoon gemaak het?**	☐	☐	☐	☐	☐
113. **Bekommer u u oor wat met u in die toekoms kan gebeur?** *Bv. dink aan om na u self om te sien of om 'n oorlas vir ander te wees.*	☐	☐	☐	☐	☐
114. **Voel u dat u in staat is om u drome, verwagtinge en wense te verwesenlik?**	☐	☐	☐	☐	☐
115. **Is u in staat om belangrike besluite in die lewe te kan maak?** *bv. om te besluit waar en by wie om te woon en hoe om u geld te spandeer.*	☐	☐	☐	☐	☐
116. **Voel u dat ander u insluit as u met hulle is?**	☐	☐	☐	☐	☐

117. **Het u in die laaste 12 maande enige groot negatiewe lewensgebeurlikheid beleef,**

bv. 'n ernstige konfliksituasie met ander of egskeiding of die dood van 'n geliefde.

- ○ Nee
- ○ Ja, spesifiseer asseblief: ....

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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 standaarde, 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?**	☐	☐	☐	☐	☐

	Baie ontevrede	*Ontevrede*	*Nie tevrede of ontevrede nie*	*Tevrede*	*Baie tevrede*

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119.	In hoe 'n mate is u tevrede met u gesondheid?	⊥H	⊥H	⊥H	⊥H	⊥H
120.	In hoe 'n mate is u tevrede met u vermoë om u daaglikse aktiwiteite uit te voer?	⊥H	⊥H	⊥H	⊥H	⊥H
121.	In hoe 'n mate is u tevrede met uself?	⊥H	⊥H	⊥H	⊥H	⊥H
122.	In hoe 'n mate is u tevrede met u persoonlike verhoudings?	⊥H	⊥H	⊥H	⊥H	⊥H
123.	In watter mate is u tevrede met u lewensomstandighede?	⊥H	⊥H	⊥H	⊥H	⊥H

124. Hoe sal u u algemene gesondheid beskryf?

- ○ Puik
- ○ Baie goed
- ○ Goed
- ○ Gemiddeld
- ○ Swak

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

- ○ 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

International Spinal Cord Injury Survey (InSCI)

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.

A collaboration of

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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]. 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 (InSCIID) 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 or contact our toll-free InSCI-helpline at 0700 523 696 631.

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Thank you again for your commitment!

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

Iinkcukacha zoMntu

1. Nceda uchaze isini sakho:

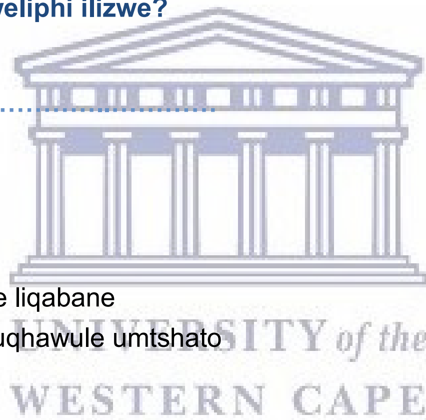
- ○ Indoda
- ○ Ibhinqa

2. Ingaba wawuzelwe ngoluphi usuku, inyanga nonyaka?

USUKU/ INYANGA/ UNYAKA

⌅ ⌅ /⌅ ⌅ /⌅ ⌅ ⌅ ⌅

3. Ingaba wawuzalelwe kweliphi ilizwe?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....

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

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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: ……………………………………………………

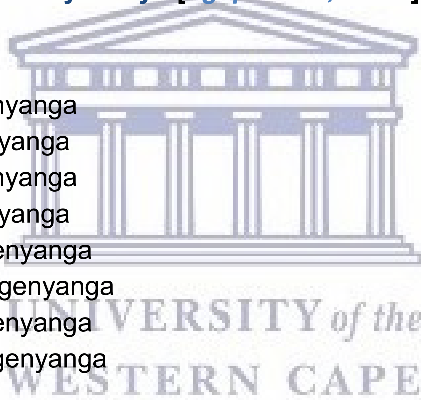
8. **Mingaphi iminyaka yemfundo okanye eyoqeqesho othe walugqiba?**

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]*

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Iimpawu zomonakalo

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.,ibhkathiriya, iintsholongwane)
- ☐ Ezinye izifo: ………………………………………………..…

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

USUKU/ INYANGA/ UNYAKA

⌅ ⌅ /⌅ ⌅ /⌅ ⌅ ⌅ ⌅

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Udlamko nemvakalelo

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

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

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Ingxaki zempilo

Ngezi ngxaki zilandelayo zempilo, nceda uthelekelele ukuba ezi ngxaki zibe ziingxaki ezinjani kwezi nyanga zintathu ziqqithileyo. 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).

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	1 Akukho Ngxaki	2	3	4	5 Ingxaki enkulu	Ukhe/ wakhe wafumana unyango lwayo?
24. **Ingxaki zokulala** *umzekelo, ingxaki zokwehla kobuthongo okanye ulala ubusuku bonke uvuke ekuseni kakhulu.*						○ Ewe ○ Hayi
25. **Ukuhambi kakuhle kwesisu** *umzekelo, urhudo,ungakwazi ukubamba ilindle ('ingozi') nokuqhina.*						Ewe Hayi
26. **Usuleleko lomchamo** *Umzekelo, izintso okanye ukusuleleka kwesinyi*						○ Ewe ○ Hayi
27. **Isinyi esingasebenzi kakuhle** *umzekelo,ukuzichamela ('iingozi'), isinyi okanye isinyi okanye amaqhuma kwizintso, ingxaki kwizintsho, umchamo ongavakali xa uphuma and umchamo ugcinakele.*						Ewe Hayi
28. **Ukuphela kwemizwa kwezesondo** *umzekelo.,ukuphelelwa yimizwa yesondo, ukuvukelwa,ubumanzi, nokufikelela kukwaneliseka ngokwesondo.*						Ewe Hayi
29. **Isimo sokwehlisa okanye ukuqinisa izihlunu** *Oku kukungakwazi ukusebenzisi amalungu omzimba ngokupheleleyo kwimidibaniso yamalungu omzimba.*						○ Ewe ○ Hayi
30. **Inkantsi yezihlunu, ukuqinelwa zizhlunu** *Oku kubhekisa kwiintshukumo zezihlunu ezingalawulekileyo ezinjengokushuma kwezihlunu ngokungalawulekiyo okanye inkantsi yezihlunu.*						○ Ewe ○ Hayi
31. **Izilonda ngenxa yokuhlala ndawonye, amatyhungutyhungu** *Ezi zilonda zivela njengerhashalala yesikhumba okanye ububomvu kwaye isenokuqhubekeka ibesisilonda esinobumdaka esingapholiyo.*						Ewe Hayi
32. **Iingxako zokuphefumla** *Iimpawu neengxaki zokwasuleleka ziquka iingxaki zokuphefufumla nokunyuka kwemikhunya.*						○ Ewe ○ Hayi
33. **Umonzakalo obangelwe kukulahleka**						○ Ewe ○ Hayi

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	1 Akukho ngxaki	2	3	4	5 Ingxaki inkulu kakhulu	Ukhe/ wakhe wafumana unyango lwayo
kwemvakalelo *Umzekelo, izilonda zokutsha ezinololwelo olushushu okanye ukuhlala phantsi ixesha elide kufutshane nehitha okanye umlilo.*						
34. Iingxaki zokuhamba kwegazi *Oku kuquka ukudumba kwemithambo, iinyawo, imilenze okanye izandla, okanye uukwenzeka kwamahlwili egazini.*						○ Ewe ○ Hayi
35. Ukunyukelwa luxinizelelo lwegazi ngokukhawuleza *Iimpawu zokhawuleza kunyuke uxinizelelo lwegazi nokubila, amabala kwisikhumba, iingongoma, ukungabini owexeshana nentloko ebuhlungu.*						○ Ewe ○ Hayi
36. Ukufutheka ngenxa yokuma ixesha elide *Oku kuquka imvakalelo yokuba nesiyezi kulandela ukutshintsha isikhundla sokuma.* *Oku kubangelwa kukuhla koxinizelo lwegazi.*						○ Ewe ○ Hayi
37. Intlungu *Ukuba neentlungu kubomi bemihla ngemihla.*						Ewe Hayi

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

Akukho ntlungu ↔ *Iqaqamba kakhulu*

○										
0	1	2	3	4	5	6	7	8	9	10

39. Nceda uchaze iingxaki zempilo ezongezekileyo ezintlanu ezikuthukuthezelayo:

Akukho zingxaki zempilo zongezekileyo endinazo

....

....

....

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. ...

. ...

40. Nceda uphawule isimo sakutshaya:

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

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Imisetyenzana nokuthatha inxaxheba

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

Kwezi veki zine zidlulileyo, kukangakanani ngokwengxaki othe wahlangabezana nayo...	*1 Akukho ngxaki*	*2*	*3*	*4*	*5 Ingxaki enkulu*
41. ... ukuqhubekeka nezinto zakho zosuku?	☐	☐	☐	☐	☐
42. ... ukumelana noxinzelelo lwakho?	☐	☐	☐	☐	☐
43. ...ukwenza izinto ezizakufuna usebenzise izandla zakho kunye neminwe, njengoku phakamisa izinto okanye ukuvula ikhonteyina?	☐	☐	☐	☐	☐
44. ...ukufikelela apho ufuna ukuya khona?	☐	☐	☐	☐	☐
45. ...ukusebenzisa izithuthi zikawonkewonke?	☐	☐	☐	☐	☐
46. ... ukusebenzisa isithuthi zabucala?	☐	☐	☐	☐	☐
47. ...ukujongana nempilo yakho,ukutya kakuhle, ukuzilolonga okanye ukusela amayeza akho?	☐	☐	☐	☐	☐
48. ...ukwenza umsebenzi wakho wasendlwini uwugqibe?	☐	☐	☐	☐	☐
49. … ukunikeza uncedo okanye inkxaso kwabanye?	☐	☐	☐	☐	☐
50. … ukunxibelelana nabanye abantu?	☐	☐	☐	☐	☐
51. … ukuthandana?	☐	☐	☐	☐	☐
52. … ukwenza izinto zokuphumla okanye ukuzonwabisa?	☐	☐	☐	☐	☐
53. … ukuqhawukelwa ngumphefumlo xa uzilolonga?	☐	☐	☐	☐	☐
54. Uyakwazi ukuhlala phantsi ungaxhaswanga? ○ Hayi ○ Ewe → **Ingaba kuyingxaki kangakanani ukuhlala**	☐	☐	☐	☐	☐

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phantsi ixesha elide njengma-30 emizuzu?					
55. Uyakwazi ukuma ungaxhaswanga?	⊥H	⊥H	⊥H	⊥H	⊥H

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☐ Hayi ☐ Ewe → **Ingaba kuyingxaki kangakanani ukuma ixesha elide njengma 30 emizuzu?**	

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*	*Uwukwaz i*
56.	**... ukuphakama emgangathweni ukusuka phantsi xa ubulele ngomqolo?**	☐	☐	☐	☐	☐
57.	**ukutyhala ucango olunzima luvuleke?**	☐	☐	☐	☐	☐
58.	**...ukusuka xa ubuhleli ecaleni kwebhedi ufuna ukucambalala ngomqolo?**	☐	☐	☐	☐	☐

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Ukuzimela kwizinto ozenzayo ngosuku lwakho

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

59. Ukutya nokusela

- ○ Ndidinga ukutyiswa ngophayiphu abafakwa emqaleni okanye esisuswini
- ○ Ndidinga ukuncediswa xa ndisitya / ndiseka
- ○ Ndidinga 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 isephu nokosula, nokusetyenziswa amanzi etepu.

- ○ Ndidinga ukuncediswa kangangoko
- ○ Ndidinga ukuncediwa 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 isephu nokosula, nokusetyenziswa amanzi etepu.

- ○ Ndidinga ukuncediswa kangangoko
- ○ Ndidinga 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 izixhasimzimba (umz. isixhasi-ngalo, isixhasi-ntamo, ikhosethi).

- *Iimpahla ezinxibeka lula zezo zingenamaqhosha, ziziphu okanye iileyisi*
- *Iimpahla ezinxibeka nzima zinamaqhosha, iziziphu okanye iileyisi*

- ○ Ndidinga ukuncediswa kangangoko
- ○ Ndidinga 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

63. Ukunxiba umzimba ongezantsi

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

- *Iimpahla ezinxibeka lula zezo zingenamaqhosha, ziziphu okanye iileyisi*
- *Iimpahla ezinxibeka nzima zinamaqhosha, iziziphu okanye iileyisi*

- ○ Ndidinga ukuncediswa kangangoko
- ○ Ndidinga 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.

- ○ Ndidinga uncedo kangangoko
- ○ Ndidinga uncedo kancinane
- ○ Ndiyazenzela xa kukho izixhobo zokuncedisa
- ○ Ndiyazenzela ngaphandle kwezixhobo zokuncedisa

65. Ukulawula isinyi

Nceda ucinge ngendlela okhupha ngayo umchamo kwisinyi.

A. Ukusetyenziswa kwekhathitha efakwe ngaphakathi

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

B. Ikhathitha yesiqabu

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

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***C.* Ukusetyenziswa kwesixhobo sokudontsa sangaphandle** *.(umz. ikhathitha yekhondom, iinapkeni)*

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

66. Ukulawula ukuzithuma

A. Ingaba udinga uncedo kulawulo lokuzithuma *(umz. ukufaka amayeza ngaphantsi)***?**

- ○ Ewe
- ○ Hayi

B. Ukuzithuma kwam…

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

C. Ukuzithuma okungalawulekileyo ("iingozi") kwenzeka …

- ○ Ntsuku zonke
- ○ Kanye ukuya kwisithandathu ngeveki

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- 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.

- Ndidinga uncedo kancinane kwaye andikwazi ukuzicoca ngokwam
- Ndidinga uncedo kancinane kodwa ndikwazi ukuzicoca ngokwam
- Andidingi luncedi kodwa ndidinga izixhobo zoncediso (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 <u>ukuya esitulweni esihambayo</u>

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

70. Ukuhambahamba <u>imigama emifutshane (iimitha ezi-10 ukuya kwi-100)</u>

Ndisebenzisa isitulo esihambayo. Ukuhambahamba, ...

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

Ndihamba <u>imiganyana ephakathi</u> 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 ngekheyini enye
- ndihamba ngesixhasi-mlenze kuphela (umz. izixhasi-mlenze)
- ndihamba ngaphandle kwezincedisi

Umsebenzi

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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 uthe 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':

....

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

- ○ Iiyure ezingaphezulu
- ○ Iiyure ezingaphantsi
- ☐ Isixa esifanayo

	1 Akukho ngxaki	*2*	*3*	*4*	*5 Kukho ingxaki enkulu*
79. Ingaba kuyingxaki engakanani ukuba wenze izinto ziqhube njengoko zifunwa emsebenzini?	☐	☐	☐	☐	☐
80. Ingaba kuyingxaki kangakanani ukufikelela emsebenzini? *Umz. ukufikelela kwisakhiwo, iofisi okanye ithoyilethi yakho*	☐	☐	☐	☐	☐

	Kakhulu	*Kwinxalenye enkulu*	*Kwiinxaleny e*	*Kancinane*	*Andiyiding i tu kwaphela*	*Andinasiding o sinjalo*
81. Ingaba unazo izixhobo zokukuncedisa ongasisebenzisa xa usemsebenzini ? *umz., izixhobo ezincedisayo zekhompyutha, iitafile ezilungelelaniswayo okanye izixhasingalo /izandleokanye izixhasimilenze.*	☐	☐	☐	☐	☐	☐

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.	☐	☐	☐	☐
83. Xa ndiqwalasela zonke iinzame zam kunye nendikufezekisileyo, umvuzo wam awanelanga. *Nceda uye kumbuzo wama-87*	☐	☐	☐	☐

84. Ingaba uthanda ukuba nomsebenzi ohlawulwayo?

- ○ Ewe

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○ Hayi

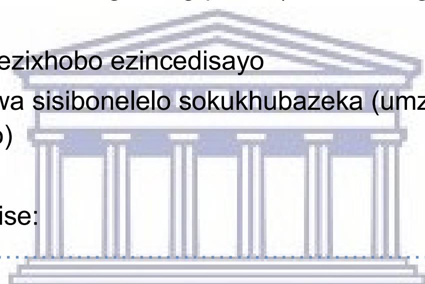
85. Ingaba uziva ukulungele ukwenza umsebenzi ohlawulayo?

○ 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
☐ Iinkonzo 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:

. ……………………………………………………………………………………..



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Iimeko 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. Ukungafikeleli okanye ukungakwazi ukufikelela kwiindawo zoluntu *Umz., ukungafikeleleki kwezakhiwo zoluntu, iipaki*	☐	☐	☐	☐
88. Ukungafikeleli okanye ukungakwazi ukufikelela kumakhaya abahlobo nezalamane	☐	☐	☐	☐
89. Iimo zezulu ezingentlanga *Umz., imozulu, ixesha lonyaka, amaqondo obushushu, ulophu*	☐	☐	☐	☐

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90.	**Izimvo zoluntu ezingentlanga ngakubantu abakhubazekileyo** *umz., ukucalula, ityheneba, ukungahoyi*	☐	☐	☐	☐
91.	**Izimvo ezingentlanga zosapho nezalamane malunga nokukhubazeka kwakho** *umz., ukucalula, ukunqongophala kwenkxaso, imeko yokukhuselo olugqithisileyo*	☐	☐	☐	☐
92.	**Izimvo ezingentlanga zabahlobo bakho malunga nokukhubazeka kwakho** *umz., ukucalula, ukunqongophala kwenkxaso, imeko yokukhuselo olugqithisileyo*	☐	☐	☐	☐
93.	**Izimvo ezingentlanga zabamelwane, abantu obaziyo noogxa bakho emsebenzini malunga nokukhubazeka kwakho** *umz., ukucalula, ukunqongophala kwenkxaso, imeko yokukhuselo olugqithisileyo*	☐	☐	☐	☐
94.	**Ukunqongophala okanye ukungabikho kobungcaphephe kwezincedisi ezizakwenza ukwazi ukuhambahamba imiganyana emifutshane** *Umz. Izitepusi ezihamba ngombane, ikheji, izincedisikuhamba okanye isitulo esinamavili*	☐	☐	☐	☐
95.	**Ukunqongophala okanye ukungafaneleki kwezinto zothutho kwimigama emide** *Umz. ukunqongophala kweemoto ezifanelekileyo okanye kunzima ukusebenzisa izithuthi zikawonke wonke*	☐	☐	☐	☐
96.	**Ukunqongophala okanye ukunganeliseki ngoncedo lwamanesi kunye neenkonzo zenkxaso** *Umz. Uncedo lwezempilo ekhaya okanye ukuncediswa wena buqu.*	☐	☐	☐	☐
97.	**Ukunqongophala okanye ukungoneliswa ngamayeza kunye nezixhobo nezibonelelo zonyango** *Umz., umbhobho womchamo, izibulali-ntsholongwane, izixhasi, imiqamelelo*	☐	☐	☐	☐
98.	**Iimeko zeengxaki zezimali** *Umz., ukunqongophala kwemali*	☐	☐	☐	☐
99.	**Ukunqongophala okanye ukungoneli kwezixhobo zokunxibelelwano** *Umz., ukunqongophala okanye ukunganeli kwezixhobo zokubhala, iikhompyutha, ifowuni, iimawusi*	☐	☐	☐	☐
100.	**Ukunqongophala okanye ukungoneli kweenkonzo zikarhulumente** *umz., impepha ezixhasa ukukhubazeka okanye ezinye izibonelelo*	☐	☐	☐	☐

Inkonzo zempilo

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101. Ngobani ababoneleli ngononophelo 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 ngeenkonzo zonakekelo 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:	*Lunge kakhulu*	*Lungile*	*Lungaluhlanga kodwa lungelubi*	*Lubi*	*Lubi kakhulu*
103. ...amava akho ngokuphathwa ngentlonipho?	☐	☐	☐	☐	☐
104. …ababoneleli ngonakekelo lwempilo bazichaze njani izinto kuwe?	☐	☐	☐	☐	☐
105. …amava akho ekwenziweni kwezigqibo ngonyango lwakho?	☐	☐	☐	☐	☐

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

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- ☐ 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:

. ...

	Ndanelisele kakhulu	*Ndanelisekile*	*Ndaneliseke ndinganelisekanga*	*Andanelisekanga*	*Andanelisekanga tu kwaphela*
107. Ngokuphangaleleyo, ingaba waneliseke kangakanani ngeenkonzo zempilo eziqhutywa kummandla wakho?	☐	☐	☐	☐	☐

Iimeko zobuqo

Le mibuzo ilandelayo ingokuba usibona njani isiqu sakho.

	1 Andizithembanga tu	*2*	*3*	*4*	*5 Ndizithembe kakhulu*
108. Uzithembe kangakanani ukuba ube ungafumana iindlela zokufumana loo nto uyifumana ukuba kukho umntu okuphikisayo?	☐	☐	☐	☐	☐
109. Uzithembe kangakanani ukuba ungajongana ngqo neziganeko ezingalindelekanga?	☐	☐	☐	☐	☐
110. Uzithembe kangakanani ukuba ube ungagcina uqhagamshelwano nabantu ababalulekileyo kuwe?	☐	☐	☐	☐	☐
111. Uzithembe kangakanani ukuba ungazigcina ukwimpilo entle?	☐	☐	☐	☐	☐
112. Ingaba ucinga ukuba ukuphila nomonzakalo komnqonqo kukwenze wangumntu owomeleleyo?	☐	☐	☐	☐	☐
113. Ingaba unenkxalabo yokuba	☐	☐	☐	☐	☐

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kuza kwenzeka ntoni kwixa elizayo? *Umz., cinga ngokungakwazi ukuzinakekela, okanye ukuba ngumthwalo kwabanye kwixesha elizayo*					
114. Ingaba ucinga ukuba uza kukwazi ukufezekisa amaphupha, amathemba, neminqweno yakho?	☐	☐	☐	☐	☐
115. Ingaba ukhe wenze izigqibo ezinkulu ngobomi bakho? *Umz. ukugqiba apho uza kuhlala khona okanye ingaba uza kuhlala nabani, uza kuyichitha njani imali yakho*	☐	☐	☐	☐	☐
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

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

Kwezi ntsuku zilishumi elinesine zidlulileyo ...	*Iphantsi kakhulu*	*Iphantsi*	*Ayikho phantsi kodwa ayikho phezulu*	*Iphezulu*	*Iphezulu kakhulu*
118. Ingaba ungayithelekelela kowuphi umyinge ikhwaliti yobomi bakho?	☐	☐	☐	☐	☐

	Andanelisekanga kakhulu	*Andanelisekanga*	*Ndaneliseke ndinganelisekanga*	*Ndanelisekile*	*Ndaneliseke kakhulu*
119. Ingaba waneliseke kangakanani ngempilo yakho?	☐	☐	☐	☐	☐
120. Ingaba waneliseke kangakanani ngokwenza imisetyenzana yemihla ngemihla?	☐	☐	☐	☐	☐
121. Ingaba waneliseke kangakanani ngesiqu sakho?	☐	☐	☐	☐	☐

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122.	Ingaba waneliseke kangakanani ngobudlelwane bakho nabanye abantu?					
123.	Ingaba waneliseke kangakanani ngeemeko zakho zokuphila?					

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!

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