Activity limitations and participation restrictions four years after traumatic spinal cord injury in Cape Town, South Africa

Vania van Wyk

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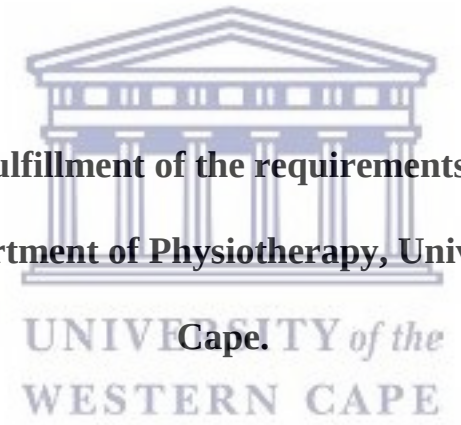

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Supervisor: Dr Conran Joseph

Co-Supervisor: Associate Prof. Nondwe Mlenzana

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Declaration

I declare that "Activity limitations and participation restrictions four years after traumatic spinal cord injury in South Africa" is my own work, that it has not been submitted for any degree or examination in any other university, and that all the resources I have used or quoted have been indicated and acknowledged by complete references.

Name: Vania van Wyk **Date:** 09 November 2018

Signed: 

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Dedication

This thesis I dedicate to my two beautiful children, Annabelle and Daniel van Wyk. Thank you for your patience with mommy for the past few years. This thesis is evidence that, with Jesus in your boat you can achieve anything. I love you with all my heart.

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I thank my heavenly father for his unconditional love, and for making this is reality. For opening doors that no man can shut. He is my source.

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Key words

Spinal Cord Injury

Trauma

Traumatic Spinal Cord Injury

Activity

Participation

South Africa

Cape Town

Population based cohort study

International Classification of Functioning, Disability and Health

Outcome Measures

Rehabilitation

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Abstract

The distressing event of Spinal Cord Injury (SCI) leads to complete or incomplete injury, and results in many complications such as such as neurogenic shock, cardiovascular disease, temperature regulatory problems, respiratory complications, dysphagia, thromboembolism, and pressure ulcers amongst others. These complications limit the individual's functioning and participation. Participation is fruitful and meaningful when you are actively involved in a specific activity. To understand the lack of participation within a specific setting, it is important to know what the limitations in activities are, and what causes these limitations. The goal of rehabilitation should be to reintegrate patients back into the community so that they can fulfil their roles.

Aim: The aim of the study was (1) To determine included participants' socio-demographic and injury characteristics; (2) To describe healthcare services received by people living with long-term Traumatic Spinal Cord Injury (TCSI) over the past 12 months; (3) To determine the point prevalence of common activity limitations of survivors of TSCI four years after injury; (4) To determine the point prevalence of participation restrictions of survivors of TSCI four years after injury; and (5) To determine factors associated with activity limitations and selected participation restrictions four years after injury.

Methodology: A cross-sectional design, founded on a previous prospective population-based cohort study which aimed at determining the incidence and aetiology of persons with TSCI, was used to determine the point prevalence of activity limitations and participation restrictions four years after injury. Out of the 145 participants from the baseline study, 87 people were accounted for. Of these 87 people, 21 had died and 11 could not be accessed to complete the surveys. The sample size was therefore 55. The study was conducted in the Province of the Western Cape in South Africa, in the City of Cape Town metropolitan. A standardised survey

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investigating health and functioning after TSCI, the International SCI Community Survey (InSCI), was used in this study. The InSCI covers areas of healthcare utilisation, activity, participation, and secondary medical conditions. Data were captured on a Microsoft Excel spreadsheet then summarized and visualized. The data were then coded and transferred to SPSS for analysis. A report of the most common activity limitations and participation restrictions was compiled. Ethical clearance was obtained from the University of the Western Cape's Biomedical Research Ethics Committee.

Results: The mean age of the participants (N=55) was 36 with 84% being males and 69% of which were single. Fifty-three percent of the participants had TSCI due to assault. With regards to care provision and satisfaction with health care services, 63% accessed general practitioners and primary physicians. Only a small percentage accessed a physiotherapist (20%) and an occupational therapist (9%). In terms of overall satisfaction, two thirds of the cohort were satisfied with services received. Regarding activity limitations, 22% of the cohort was unable to dress the lower body as well as bath the lower body. Concerning participation restrictions, 22 % of the participants had a substantial problem using public transport. With regards to participation at work, 60% received vocational rehabilitation and 22% are currently engaged in paid work. The only independent factor related to self-care activity was level of injury, where tetraplegia had more problems than paraplegia.

Conclusion: This study found that persons continued to experience limitations and restrictions four years post TSCI. Only one fifth of the participants engage in paid work. Based on the research outcomes, it is evident that more comprehensive rehabilitation and follow up care are required to address the complex issues after TSCI.

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Chapter 1

Introduction

This chapter defines spinal chord injury (SCI) and highlights the effect it has on the individual. A comparison is drawn between the epidemiology of SCI in different countries as well as highlighting the complex sequel of complications after injury. A problem statement is made, the research objectives and aim are stated, and the significance of the study is explained.

1.1 Background to the study

A SCI is defined as "…damage to the spinal cord resulting from trauma (e.g. a car crash or fall) or from disease or degeneration (e.g. cancer)" (World Health Organization & International Spinal Cord Society, 2013). Information, either sensory, motor or both, are carried to the brain via the spinal cord, and damage to this vital structure results in either a decrease or a loss of information delivery. Movement, sensation and body organ function are affected below the level where the injury occurred, resulting in either partial or complete loss of function (Nas et al., 2015). A SCI therefore results in a myriad of body function and structure problems which influence human functioning within various life areas (Anderson, 2004). Comprehensive services: acute, rehabilitation and community based, are required to address the complexity of patient problems presenting with SCI (Wing, 2008). The individual's functioning within the home and community is affected in multiple ways and they have to adapt to difficult situations. Rehabilitation of patients with SCI is important so that they are able to function and have a better quality of life within the family and community (World Health Organization [WHO], 2011). The rehabilitation of patients is often a difficult process within the community due to the interaction between personal and environmental factors.

The epidemiology of traumatic spinal cord injury (TSCI) is better known than for non-traumatic SCI. In developed countries, the incidence of TSCI is 13.1/million/year (Chiu et al., 2010). The

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incidence of TSCI in a developed country like Canada is as low as 3.6 per million per year (Jazayeri, Beygi, Shokraneh, Hagen & Rahimi-Movaghar, 2015). The incidence of TSCI in developing countries is estimated at 25.5 per million per year (95% confidence interval [CI]: 21.7-29.4 per million per year; Rahimi-Movaghar et al., 2013). In South Africa, however, the incidence rate of TSCI is among the highest in the world at 76 per million persons (Joseph et al., 2015). Of further interest is the unique patient profile and leading cause of TSCI, i.e. assault, which prompts the need to investigate the extent to which current management plans address issues pertinent to survivors in South Africa.

Management of SCI patients requires a systematic health care plan grounded within an evidence-based approach (Wing, 2008). It has been recommended since the mid-twentieth century that survivors of TSCI be provided with comprehensive and specialist management. However, many countries, including South Africa, have yet to fully implement such an approach that is accessible to all (Joseph et al., 2017). A systematic approach is characterised by the prompt implementation of key logistical processes and interventions which are linked to increased survival, improved neurological recovery, reduced complications and therefore improved quality of life (Chamberlain, Meier, Mader, Von Groote & Brinkhof, 2015; Furlan, Noonan, Cadotte & Fehlings, 2011). In South Africa, only a few specialised acute care facilities are available, of which almost all require private medical insurance. However, less than 20% of citizens have access to these facilities, leaving the rest to be managed in non-specialised settings (Joseph et al., 2015).

In South Africa, those who have access to private health insurance, and those in the more urbanised areas will have access to a more comprehensive health care with better-equipped facilities. For the non-private patient there can be a delay of an average of 10 days before they receive much needed stabilisation surgery (Joseph & Nilsson-Wikmar, 2016). There are many possible contributing factors to this: short staffed; lack of bed availability; lack of theatre time;

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lack of resources; or lack of expertise. Patients are often left with secondary complications because of this long wait (Joseph & Nilsson-Wikmar, 2016). There is one main public funded rehabilitation centre for SCI in Cape Town. Admissions are mostly approved based on age; potential for recovery from a neurological standpoint; and motivation of the client (Joseph, Scriba, Wilson, Mothabeng & Theron, 2017). It is also evident that the criteria for selection for rehabilitation are based on the patient prognosis, those with a better prognosis being favoured over those with a lesser chance of recovery. Therefore, access is poor and the need exists to investigate human functioning, including activity and participation of those who received and did not receive rehabilitation following a long-term perspective.

In order to accurately determine the extent of activity and participation, operational definitions need to be used. As such, activity, according to the World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICF), is defined as any task or action one does; it is a physical action. This is related to one's personal, social or occupational being. Therefore, activity limitation is difficulty experienced while trying to execute a task or action (World Health Organization & International Spinal Cord Society, 2013). Participation is one's involvement in a situation, their contribution or engagement at any given time. Participation restriction is defined, by the WHO, as a problem experienced by an individual in involvement in life situations (World Health Organization & International Spinal Cord Society, 2013). This life situation is in the area of employment, within the community or even in the home of an affected individual. It further denotes social roles.

The goal of health care systems is on livelihood and restoring functioning, this is expressed as maintaining and restoring functional independence, participation in society, and living a fulfilled life with SCI. The philosophy is to restore optimal functioning within the community and ultimately to return to previous employment. A systematic review showed a strong link between physical activity and quality of life as well as functional independence (Kawanishi &

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Greguol, 2013). Functional independence and quality of life was improved when aerobic and resistance exercises were combined (Kawanishi & Greguol, 2013), highlighting the role of neurorehabilitation. The ICF, as depicted in Figure 1, demonstrates the interaction between a person with a health condition and his/her contextual environment. This environment includes the societal response towards the management of health conditions.

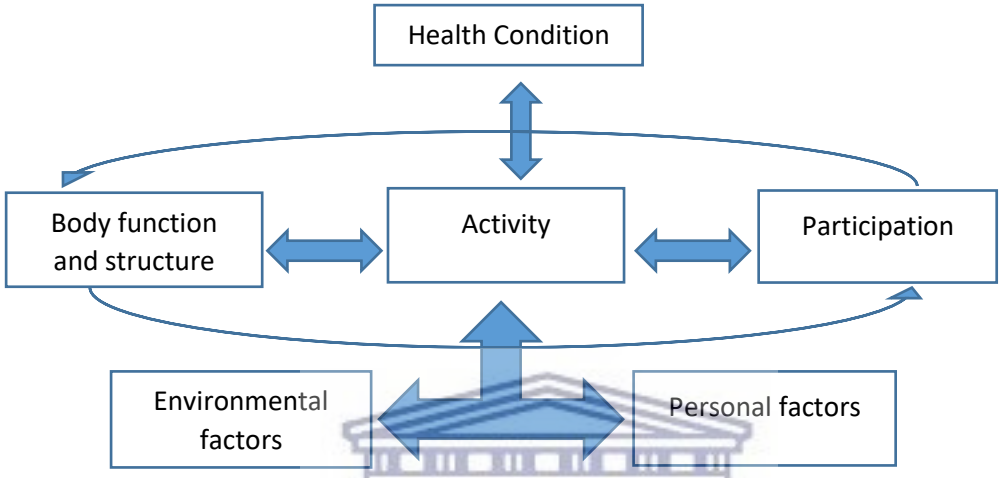

Figure 1. *The International Classification of Functioning, Disability and Health* (World Health Organization, 2013)

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It is expected that patients regain some function during in-patient rehabilitation, which consist of approximately 68 days for paraplegic patients and 86 days for tetraplegic patients in South Africa (Joseph et al., 2017). Certain activity and participation needs of patients are often left unmet following this care episode (Beauregard, Guidon, Noreau, Lefebvre & Boucher, 2012; Joseph et al., 2013). Because some patient needs are left unmet, there is a need for ongoing community-based intervention. Community-based rehabilitation has therefore gained momentum as means of addressing activity limitations and participation restrictions once persons with disabilities are back in their pre-injury environment/community. Patients are therefore discharged into the community where they should receive out-patient rehabilitation to assist in ongoing care. However, they have difficulty accessing these services, which are

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limited by availability of community rehabilitation, transport, finances and mobility to re-enter the system (Joseph et al., 2017).

1.2 Problem statement

Healthy ageing following TSCI depends on the absence of secondary medical complications, optimal levels of activity and participation, and a well-functioning healthcare system that responds to threats in a time-sensitive manner (Chamberlain et al., 2015; Savic et al., 2017). However, no consistent chain-of-healthcare is available for all persons with TSCI in South Africa, leaving only a certain proportion receiving acute and inpatient rehabilitation. The local literature further highlights that approximately 85% still have problems with independent mobility and 70% with stair management at the end of inpatient rehabilitation (Joseph et al., 2013). In order to improve participation within the community, firstly acceptance of self, overcoming of barriers, an active support system and being involved in change is necessary (Joseph, Wahman, Phillips & Nilsson-Wikmar, 2016). Planning, preparing and paying constant attention to an altering environment, will assist to regain a sense of normality within the society (Suarez, Levi & Bullington, 2013). Moreover, outpatient rehabilitation is not provided to all persons with TSCI – the platform that is used to address issues with community mobility, participation and return to productivity.

The extent to which rehabilitation services was accessed four years after injury remains unknown. In order to promote healthy ageing following TSCI, it remains imperative to assess activity limitations and participation restrictions to strengthen health systems for this vulnerable group. Understanding the factors surrounding those experiencing activity limitations and participation restrictions could be used to target those at greater risk.

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1.3 Aim

To evaluate the socio-demographic circumstances, healthcare services and satisfaction of healthcare services, as well as activity and participation of people living with long-term TSCI in the City of Cape Town region, South Africa, four years after injury onset.

1.4 Objectives

1. To determine included participants' socio-demographic and injury characteristics.
2. To describe healthcare services received and the satisfaction of health care services of people living with long-term TCSI over the past 12 months.
3. To determine the point prevalence of common activity limitations of survivors of TSCI four years after injury.
4. To determine the point prevalence of participation restrictions of survivors of TSCI four years after injury.
5. To determine factors associated with activity limitations and selected participation restrictions four years after injury.

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1.5 Research questions

1. What are the socio-demographic and injury characteristics of survivors of TSCI for years after injury?
2. Which healthcare services did people living with long-term TSCI receive, and how satisfied were they with these services?
3. What are the most common activity limitations of survivors of TSCI four years after injury?
4. What are the most common participation restrictions of survivors of TSCI four years after injury?

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5. Which injury and contextual factors are associated with activity limitations and participation restrictions four years after injury?

1.6 Significance of the study

A TSCI results in a compromise in human functioning, quality of, and satisfaction, with life. Injury manifestations often lead to decrements in functioning. However, little is known about the activity limitations and participation restrictions after long term TSCI in South Africa. This information is required to assess the impact of the injury, as well as the effects of the healthcare system on important patient-centred outcomes. With the goal of healthcare systems towards addressing important human functioning outcomes, this study will potentially assist with the recommendation of targeted rehabilitation interventions in remediating unmet activity and participation needs.

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Chapter 2

Literature review

This chapter focuses on the epidemiology of TSCI. It will expand on the incidence, prevalence, aetiology and mortality of TSCI within the South African context and refer to research concerning this around the world, comparing developing countries to developed countries. Furthermore, operation definitions for activity and activity limitations are defined, highlighting the limitations, as experienced by those affected with TSCI. Participation and participation restrictions will also be explored. A description of outcome measures is provided, making reference to what each outcome measure covers. The chapter also reviews the literature on factors that typically influence activity limitations and participation restrictions. Lastly, it explains rehabilitation, its importance and the effect it has on the individual and the family. It also addresses rehabilitation of SCI in South Africa and the main problems addressed during the rehabilitation period.

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2.1 Epidemiology

The occurrence of SCI has an immeasurable effect on the individual's life. The damage caused is often permanent and has a lifetime effect on the individual as well as the family and support structures. Not only is the quality of life decreased, but the mortality rate is higher with these patients as well (Hagen, 2015; Joseph & Nilsson-Wikmar, 2016). The challenge that exists within South Africa is with the allocation of resources and development of preventative strategies for the specific needs of the client with Spinal Cord Injury (SCI) because of the lack of epidemiological studies within the country (Joseph et al., 2016). No SCI register exist within South Africa, which means there is no track record of the incidence of this devastating and life altering condition (Joseph et al., 2015). However, the epidemiology of TSCI is slowly being

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unveiled in South Africa (Joseph et al., 2017; Pefile, Mothabeng & Naidoo, 2018; Sothmann, Stander, Kruger & Dunn, 2015)

In South Africa, the incidence rate of TSCI is among the highest in the world at 76 per million persons (Joseph et al., 2015). Worldwide statistics showed in 2015 that an approximate number of 40 million SCI occur annually (Nas et al., 2015). These are mostly in men between the ages of 20-35. The most common causes for these injuries were; traffic accidents, gunshot injuries, knife injuries, falls and sports injuries (Nas et al., 2015).

A study done on TSCI, in Cape Town, consisted of a population of which 85.5% were males, with a mean age of 33.5. The primary cause of injury was assault (59%), followed by transportation and falls (Joseph, 2016). Assault was further classified as gunshot wounds, which occurred more than stab wounds and non-penetrable injuries. A similar study done in Botswana indicated the incidence was 13 per million persons. Seventy-one percent of this population was males with a mean age of 45. Road traffic crashes were the main cause of TSCI. Motor complete tetraplegia was common with injuries sustained in the cervical region C1-C4 (Löfvenmark, 2016). Mortality rate of TSCI patients in Botswana was 20%, where Sweden reported a mortality rate of zero percent (Löfvenmark et al., 2015).

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2.2 The International Classification of Functioning, Disability and Health

The ICF is an international framework that aids in the classification and understanding the impact of any disability on functioning as well as the health of those affected by any health condition or disease (World Health Organization [WHO], 2002). The ICF guides health care workers regarding the abilities of the person with a health condition. It helps identify what the restrictions are, compared to the level of previous function. It is a holistic framework, which looks at activity, participation, body function and structure, as well as the environmental

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conditions (WHO, 2002). The ICF recognises that each individual will respond differently to disability due to the distinctive environmental contributions (Joseph et al., 2016). The primary aim of the ICF is to look at the health and functioning of the individual within the environment, rather than having the focus on the ill health and incapacity of the individual (WHO, 2002). This conceptual model provides a basis for individualised treatment and management.

2.3 Activity limitation after TSCI

Illustrated in the ICF is the relations between health condition, body functions and structures, activities, participation and related factors (Suttiwong, Vongsirinavarat, Chaiyawat & Vachalathiti, 2015). Impairment following injury results in activity limitations. Insult to the sensory, motor and nervous systems during SCI results in a less active life, where individuals with injuries do not enjoy a full and productive life (Vissers et al., 2008). Difficulty in executing tasks alters one's quality of life (QOL). QOL improves if rehabilitation assists to reduce activity limitations. Activity happens within a context, and not all rehabilitation services consider the context when training patients. Mobility, stair climbing and transfers from floor to wheelchair were found to be the most prevalent activity limitation in patients following in-patient rehabilitation (Joseph et al., 2013). Bathing of the lower limbs, transfers from the wheelchair to the car, and toileting were the three limitations where patients showed greatest improvement from admission to discharge. Joseph et al. (2013) highlight that the highest level of independence is in feeding, grooming and respiration. This was also found to be true in a study done in the Netherlands (Post, Dallmeijer, Angenot, van Asbeck & van der Woude, 2005). Rehabilitation appears to be useful in essential activities. However, mobility tasks still require interventions after inpatient rehabilitation.

A study done in 16 European specialized SCI rehabilitation centres indicated that there was an increase in function during activities of daily living (ADLs) post rehabilitation (Wirth, van Hedel, Kometer, Dietz & Curt, 2008). The ADLs included grooming, feeding, self-care, bladder

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management, walking and transfers (Wirth et al., 2008). Vissers et al. (2008) established that problems with self-care was the biggest barrier shortly after discharge.

A study done by Anderson (2004) on the priorities of the SCI population, depicted the difference in priorities between the paraplegic and tetraplegic populations. Anderson, Vogel, Willis, and Betz (2006) showed that QOL will be improved for the tetraplegic population, should they regain arm and hand function, as expressed by 48.7% of the cohort. Sexual function was ranked second most important (13%), and thirdly upper body/trunk strength and balance as improvements in this area would improve patient's functionality. In this same study, the paraplegic population indicated that QOL would be improved if they regained sexual function (26.7%), had improved bladder and bowel function and if autonomic dysreflexia was eliminated (18%), and if they had increased upper body/trunk strength and balance (16.5%; Anderson, 2004). It is clear that different functioning priorities exist between persons with tetraplegia and paraplegia. Rehabilitation personnel should be aware of these disparities in goals.

2.4 Participation restrictions after TSCI and associated factors

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Participation includes taking part in or the involvement in life situations according to the ICF. As expressed in the United Nations Convention on the Rights of Persons with Disabilities, participation is a broad concept. Within the field of SCI, participation is seen as a concept which transcends physical capabilities, but includes social roles and responsibilities (Dijkers, 2005; WHO, 2002).

According to Anderson (2004), individuals with SCI have reported limited access to community resources. In addition to this, limited access to social support, marriage and community integration were experienced (Anderson, 2004). Anderson (2004) also notes that the majority of SCI patients believe that you need exercise to recover functionally, but most of these patients do not have access to trained therapists within their community.

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In South Africa, inaccessibility to the environment was identified as a major barrier to social participation and integration (Joseph et al., 2017). In spite of attempts by local authorities to improve this, more than 30 years after TSCI, the same challenges exist (Joseph et al., 2017). No SCI-specific legislations have been put in place to facilitate participation and promote equal access to services and opportunities for work and social engagement (Joseph et al., 2017). In addition, according to Joseph et al. (2017), there is a lack of recreational facilities, transport and access to the environment. Survivors of TSCI in South Africa feel that personal relationships are affected after SCI due to a lack of intimacy, energy and mobility challenges (Joseph et al., 2017).

Individuals with SCI need access to resources and require acceptance in order to participate. Bearing in mind the individual's disability, participation is unique to every individual. Personal and cultural aspects plays a role in participation (Maclachlan, 2014). Together with the loss of function, patients usually lose employment because of long periods of rehabilitation that can be costly and exhausting (Nas et al., 2015). This often results in psychosocial and economic difficulties (Nas et al., 2015).

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A study by Anderson et al. (2006) completed in the United States of America and Canada showed that 64% of participants with SCI transitioned successfully into adulthood. This success was based on independent living, life satisfaction and employment (Anderson et al., 2006). Life satisfaction is how you approach, or your attitude towards life at a specific time (Anderson et al., 2006). This is whether you are positive or negative towards life, and it influences how you will participate in life (Anderson et al., 2006). Community mobility is seen as an important part of life satisfaction (Anderson et al., 2006). According to Anderson et al. (2006), participants who lived independently were functionally more independent and more likely to participate within the community. They were also more likely to get married and have less medical

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complications. These participants were therefore more satisfied with life (Anderson et al., 2006).

Community integration could be perceived as how the individual participate within the community that they lived prior to injury. This includes how they participate in the home, social and previous employment. A study done by Whiteneck, Tate and Charlifue (1999) confirms that demographic factors as well as the characteristics of injury will have an impact on how a patient integrates back into the community. The study concludes that SCI survivors who are younger, with less neurological injury, of caucasian ethnicity, and with better education, will reintegrate with greater success (Whiteneck et al., 1999). The older an individual is at time of injury, the less likely they are at having success with reintegration (Whiteneck et al., 1999). However, the longer the period after injury, the more likely an individual is to achieve community reintegration (Whiteneck et al., 1999).

Research on the client's perspective regarding reclaiming participations after TSCI in South Africa showed acceptance or "dealing with the new self" is the most important factor to re-establish meaning (Joseph et al., 2016). Secondly, negotiating barriers to reclaim participation, then recognising a catalyst in the form of peer support to overcome these barriers, and lastly, becoming an agent (Joseph et al., 2016) are essential components for successful participation in the South African context. However, few studies have identified factors related to participation of SCI patients in South Africa. Such information could be used to facilitate improved functioning.

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2.5 Outcome measures

Up to date, there are a number of outcome measures in the field of SCIs. The American Spinal Injury Association Scale assesses impairments following SCI onset. The Spinal Cord Independence Measure III (SCIM III) and Functional Independence Measure (FIM; Linacre, Heinemann, Wright, Granger & Hamilton, 1994) investigate activity levels of SCI patients. No

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participation measure has been established yet, but core sets have been developed to indicate functioning categories, according to the ICF, which are appropriate to persons with SCI (Kirchberger et al., 2010). These core sets are not outcome measures but rather important areas of functioning specific to persons with a particular health condition. The need exists to develop outcome measures that are based on these core categories.

The SCIM III and FIM are both tools used to assess function in patients with paraplegia and tetraplegia. The SCIM III showed to be highly reliable and was found to be more sensitive to detecting functional changes, in comparison to the FIM. This sensitivity supports it validity. In the SCIM III, much attention is given to everyday tasks such as poor sphincter control and poor mobility. This affects both QOL and life expectancy and therefore rehabilitation should focus on these areas (Catz, Itzkovich, Agranov, Ring & Tamir, 1997).

The Model Disability Survey (MDS) is a generic measure that address impairments, participation restrictions, related health conditions and environmental factors. The MDS is based on the ICF where disability is seen as a relationship between the person's health condition and the environmental factors (World Health Organization [WHO], 2015). Analysis of data from the MDS can assist government with better planning for things like assistive devices and accessibility. It was cognitively tested in three rounds and was found valid and reliable (WHO, 2015). Data from the MDS aims at understanding how people live their lives and what barriers to full participation exist (WHO, 2015). Certain items of the MDS have been utilised for the purpose of this study.

Personal and environmental factors influence one's participation within a community. There is however, a lack of outcome measures to assess these factors. That being said, the WHO endorsed International Spinal Cord Injury Community Survey (InSCI) comprises of sections which address both these areas. The InSCI contains questions investigating transportation,

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finances, societal attitudes as well as communication devices. In doing so, the InSCI recognises the effect that the immediate environment has on participation in life situations.

2.6 Factors influencing activity and participation after TSCI

There are often restrictions that inhibit the full participation of patients post SCI. People participate better in their community if they have a good social support, better functional performance, had their injury at a younger age and is now an older person (Suttiwong et al., 2015). The sooner social support is addressed in the rehabilitation process; the better participation integration will occur (Suttiwong. et al., 2015). Family support was found to have a positive effect on social integration (Suttiwong et al., 2015). People who had a longer time to adapt to their injury, who were employed and had no problems with their sexual life, had better participation (Suttiwong et al., 2015). In addition, medical complications such as pressure ulcers were found to be related to activity and participation (Suttiwong et al., 2015). Pressure ulcers occurred more in participants living with parents, and these persons were less likely to get married (Anderson et al., 2006).

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To promote independence in ADLs, and to develop autonomy, ongoing rehabilitation is required (Kawanishi & Greguol, 2013). Patients who were found to be more active proved to have a better quality of life (Kawanishi & Greguol, 2013). Munce et al. (2014) concluded that support from the caregiver during activities of daily living (bathing, dressing and housework) will promote reintegration into the community. Olckers (2017) concludes mobility and quality of life is directly proportional. With increased mobility comes increased social participation. However, there is therefore a need to identify factors that are related to activity and participation which takes into account the contextual factors of clients with TSCI.

2.7 Rehabilitation

Understanding the scope and philosophy of rehabilitation practice helps the health care worker to effectively rehabilitate the disabled. Rehabilitation is the management of functioning

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and health by a multi- and interdisciplinary team (Maclachlan, 2014). Rehabilitation is defined by the WHO as: “a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments” (World Health Organization [WHO], 2011). Rehabilitation includes therapy committed to improve, maintain or restore physical activity and strength, as well as mobility (WHO, 2011).

With SCI, the rehabilitation process requires patience and time. Both the patient and the family members need to remain motivated and positive throughout this process (Nas et al., 2015). The process requires commitment from all involved. To take care of a patient during rehabilitation is costly and tiring (Nas et al., 2015). The rold of care has economical and psychological implications for the family and the patient (Nas et al., 2015). Added to this, are the physical changes that the patient’s body go through. The process of rehabilitation starts immediately and continues for years after injury (Nas et al., 2015).

Kahonde, Mlenzana, and Rhoda (2010) state that rehabilitation is needed to achieve a better quality of life and to allow the person to have the highest level of function before returning to the community. In South Africa, rehabilitation is offered at Community Health Centre’s (CHCs) by physiotherapists and occupational therapists (Kahonde et al., 2010). Rehabilitation generally starts in acute, in-patient care; this consists of general bed mobility and self-care (Kahonde et al., 2010). Not all patients have access to further rehabilitation. Those who have access, receive rehabilitation that focuses on functional independence for mobility, self-care, bladder and bowel management (Kahonde et al., 2010). The outpatient service, at community level focuses on addressing participation and community integration challenges (Kahonde et al., 2010).

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Not much research has been done on the perception of individuals with TSCI and whether or not they feel their challenges were addressed during rehabilitation. Also, further research is required to identify and understand survivors' unmet needs.

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Chapter 3

Methodology

This chapter summarises the methods used to carry out the study. The research design is described, and the research setting is documented. A description is made of the study population and sampling, as well as the inclusion criteria. An explanation is given on how data collection was done as well as the research instrument used. A description of data analysis is provided, and finally ethical considerations are addressed.

3.1 Research design

A cross-sectional design founded on a previous prospective population-based cohort (aimed at determining the incidence and aetiology of persons with TSCI for a one year period, from 15 September 2013 to 14 September 2014), was used to determine the point prevalence of activity limitations and participation restrictions four years after injury. A report of the most common activity limitations and participation restrictions four years post TSCI was compiled. This prospective, observational design allows for studying risk indicators, from baseline data, influencing outcomes of interest. Furthermore, this research design was chosen since the external validity of findings hold relevance to the entire source population.

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3.2 Research setting

The study was conducted in the City of Cape Town metropolitan, situated within the Western Cape province of South Africa. The Western Cape is one of nine provinces in South Africa situated in the southern western part of the country. The City of Cape Town's 2017 population is estimated at 4 004 793 (City of Cape Town, Feb 2017). The metropolitan consists of both urban and peri-urban areas. Within the metropolitan there is one level-one hospital with a specialised unit working alongside Tygerberg Hospital (a tertiary, academic hospital). Due to lack of limited resources in the specialised hospital, patients are seen on a referral basis from

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the secondary hospitals which is a major problem as quality of care is delayed (Joseph, 2016). Patients with SCI are seen according to a priority scale in the two available health care facilities (Joseph, 2016). Furthermore, little is known about the chain-of-care of persons with SCI, specifically whether community-based rehabilitation services are offered in the communities where patient are discharged. According to the Department of Health in South Africa, rehabilitation should start as early as possible at community level, at CHCs. These services include home visits and vocational training (Department of health, 2016). Rehabilitation can be in the form of individual or group sessions, home or work visits as well as training of community members (Kahonde et al., 2010).

3.3 Study population and sample

All 145 TSCI patients initially included in the baseline study, i.e. utilizing an inclusive sampling technique, for the period 15 September 2013 to 14 September 2014 were surveyed four years post injury upon enrolment in the study. The study population consisted of 145 consented participants of which 124 were male and 21 females. The sample size was therefore dependent on the survival status of eligible participants. Four yeas after TSCI injury, out of the 145, 87 people were accounted for. Of these 87 people, 21 had died and 11 could not be accessed. The sample size was therefore 55.

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3.4 Inclusion criteria

All participants recruited and participated in the 2013/2014 study were included in this study. Inclusion criteria for the baseline study (incidence paper) were used. The inclusion criteria were: (1) confirmed acute traumatic spinal cord or cauda equina lesion, (2) age 18 or older at the time of injury, (3) a resident of the country and of the catchment area, and (4) those who provided informed consent (Joseph et al., 2015). The only exclusion criterion in the proposed study was those who had died within the four year period after the injury and those declining to participate.

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3.5 Data collection

Patients who have participated in the 2013/2014 study investigating the incidence and aetiology of TSCIs in Cape Town study were surveyed. Eligible participants were first contacted telephonically. Participants had a choice to participate in this study and were explained the option of face-to-face or telephonic interview as mode of data collection. Participants informed the research team of their preferred mode of answering the survey. Verbal consent was obtained from those who chose to be interviewed telephonically. To ensure record of informed consent, the participants' consent statements were recorded. This audio-record is kept as proof of consent. This method of consent was approved by the University of the Western Cape's Biomedical Research Ethics Committee.

Participants provided a date and time for data collection (telephonically to face-to-face survey). Due to the extensiveness of the survey, participants were allowed to complete the survey in more than one sitting. However, the finalisation of data collection had to be within a one week time frame to ensure that their health and functioning status did not change. Signed consent was attained from those opting to be surveyed face-to-face. Confidentiality of all participants was maintained by using a unique code per participant.

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3.6 Instrumentation, validity and reliability

General mobility and whether participant can sit or stand, which enables independence, is also assessed. These questions were obtained from the MDS (Trani, Babulal & Bakhshi, 2015; WHO, 2015) as well as the Spinal Cord Injury-Functional Index-Assistive Technologies (Jette, Halbert, Iverson, Miceli & Shah, 2016). The MDS is a valid and reliable measure (WHO, 2015). Activities of daily living which was assessed, specifically how the participant feeds or drinks, how they dress and groom, how much independence they have with bowel and bladder management and how much assistance is needed with mobility and transfers. ADL related questions were derived from the Spinal Cord Independence Measure for self-report (SCIM-SR)

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The SCIM-SR is a reliable measure. The reliable coefficient for this measure is between 0.80 to 0.90 (Fekete et al., 2013).

External or environmental influences were assessed by posing questions which related to accessibility to public areas as well as home environements to the participants. The questions posed were derived from the the Nottwil Environmental Factors Inventory (NEFI; Ballert, Post, Brinkhof, Reinhardt & Group, 2015). The attitudes toward disabilities of persons in contact with the participants were examined. Furthermore, the participants were questioned on their view of the lack of assistive devices, transport, medical care and finances.

A standardised survey investigating health and functioning after TSCI, the International Spinal Cord Injury Community Survey (InSCI), was used in this study. This survey had been designed by an international steering committee with the aim to assess the lived experiences and societal response to SCI. This survey has been distributed to more than 30 countries worldwide. The InSCI survey investigates health problems of participants, and the services that they were able to access in order to manage all SCI-related issues. The InSCI further investigates the participants' activity and participation, independence with ADLs, working situations and environmental factors, and explores how these have made the participants' life easier or tougher. Care provision, and satisfaction with health care services are evaluated in terms of frequency, accessibility and quality, as perceived by the participant.

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The activity and participation section of the InSCI focusses on the daily routine and ease of household tasks for the participant. Included in this section is stress management, relaxation and intimate relationships, in addition to self-care and mobility items. This forms an important part of the holistic being in order to enable the person to function within the community.

The self-care sub-scale of the SCIM-SR was used to study predictors of activity at four years post SCI. With regards to work, the assessment tool focus on whether or not participant is back

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at previous employment, if participants are happy with their work and working hours, payment for work, as well as support at work. The work related questions was sourced from the International Labour Market Integration Assessment in SCI (Schottmüller, 2007), Swiss Spinal Cord Injury Cohort Study ("Swiss Spinal Cord Cohort Study," n.d.) and the MDS (WHO, 2015).

The entire self-administered questionnaire, comprising of 125 questions, took approximately 45-60 minutes to complete. The validated and reliable questionnaire was translated to isiXhosa and Afrikaans for those participants who did not understand English. Both the Afrikaans and isiXhosa versions were piloted amongst 20 survivors of TSCI to test face and content validity as well as reliability. The translation process that was followed included both forward and backward translation by one linguist and a health professional. Following the independent translation, a consensus meeting was held to deal with discrepancies in translation that arose. Only minor changes were required in order to obtain experiential and semantic equivalence. The test-retest reliability of the different subscales (across the Afrikaans and Isi-Xhosa versions) was found to range from 0.61-0.89, according to intraclass correlation coefficients.

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3.7 Data analysis

Data were captured on a Microsoft Excel spreadsheet then summarized and visualized. The data were then coded and transferred to SPSS for analysis. Concerning objective one and two, participant characteristics and health care services utilization was determined using descriptive statistics, and results are displayed as mean (SD), median, counts and percentages. Objectives one, two, and three, which consider health services, episodes of care, as well as activity limitations and participation restrictions, were documented descriptively. The results were then displayed as proportions (point prevalence). Subsequently, for objective five, the researcher predicted factors that were associated with activity limitations and participation restrictions using simple linear regression. The activity measure, SCIM III self-care subscale,

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produced a summary score ranging from 0-20. The researcher assessed all significant factors on univariate analysis, at $p<0.15$, for collinearity, prior to commencing with multivariate analysis. Following this procedure, all remaining factors were entered into a multivariate regression model to produce a final model. At this stage the statistical significance level was set at the conventional p value of $p<0.05$. The same procedure was followed for the prediction of return-to-work; however, binary logistic regression analysis was used.

3.8 Ethics considerations

Ethical clearance was obtained from the University of the Western Cape's Biomedical Research Ethics Committee. Written consent was obtained from participants for face-to-face interviews, while audio-recorded consent was sought from the participants who opted for telephonic interviews. All ethical principles were maintained throughout the study. The principles included being treated with dignity and respect, anonymity, confidentiality, and the right to withdraw from the study at any point in time. Participants were provided with relevant information about the study prior to being asked to sign/provide their consent statements. All participants were given the choice of comfort and convenience in terms of where they would like to complete the extensive questionnaire, i.e. via telephone, in the comfort of their homes or at the university. All data sets were in a format where personal information was de-identified and no unauthorized parties had access to the data. All data was stored in a locked filling cabinet in the co- investigator's office and unauthorized persons had no access to this cabinet. Anticipated risks for this study were minimal, however, if any harm was caused to the participants or if participants experienced any challenges or difficulties that the researcher was unable to assist with, the researcher recommended the appropriate professional and made relevant referrals for assistance. Participants also had the right to withdraw from the study at any time without negative consequences. All participants will receive information pertaining to the results of the study upon completion. This information will be accessible and with limited jargon in order for ease of understanding.

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There are no potential risks forseen. The information of his study will be used as a basis for future research.

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Chapter 4

Results

This chapter presents the analysis of the participant characteristics and health services recevied, and their activity limitation and participations restrictions. The factors associated with activity and participation are explored.

4.1 Participants' characteristics

The sample size was 55 individuals who experienced a TSCI four years ago. As indicated in Table 1, 84% of participants were male, and the mean age of the cohort was 36 years old. A total of 69% were single. According to this study, 27 (49%) participants completed higher secondary education, while 26% only completed lower secondary education, i.e. up until Grade 9. More than half (53%) of the cohort had TSCI due to assault, while 38% sustained their injury due to transport. With regard to injury level and severity, 58% had paraplegia, while 78% had incomplete injuries, i.e. some motor and/or sensory functions are still present. Lastly, 53% did not receive any spinal surgery during the acute stage of their injury and 53% had acute secondary medical complications during their acute management phase.

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Table 1. *Participants' characteristics*

Variables	N=55	%
Gender (n, %)		
Female	9	16
Male	46	84
Age*		
Mean(SD)	35.7(13.3)	
Median Range	31(21-70)	
Marital status		
Single	38	69
Married	7	13
Cohabitating or in a partnership	7	13
Separated or Divorced	2	4
Widowed	1	1
Education		
Primary	8	15
Lower secondary	14	26
Higher secondary	27	49
Post-Secondary	4	7
Short Tertiary	2	4
Aetiology		
Sport/leisure	1	2
Work	1	2
Assault	29	53
Transport	21	38
Falls	1	2
Other	1	2
Missing	1	2
Injury level		
Paraplegia	32	58
Tetraplegia	17	31
Missing	6	11
Injury severity		
Complete	12	22
Incomplete	43	78
Spinal surgery		
Received Spinal Surgery	26	47
Did not receive any surgery	29	53
Acute secondary medical complications (n, %)		
Yes	29	53
No	26	47

*Age as of 30 June 2017

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4.2 Care provision and satisfaction with health care services

Table 2 shows the type of services accessed and how satisfied participants were with services received. As shown in the table, a general practitioner or primary physician was consulted more often than any other medical professional (63%). A nurse or midwife was the second most common professional consulted (40%). Most of the participants (85%) were not admitted to a hospital in the past year. Of the 31% who required health care but could not access it, the majority had isolated reasons (65%), while 16% said it was not affordable for them to get to the health care facility. Concerning satisfaction, 56% of the cohort indicated that they were treated with due respect, 47% said medical information was well explained to them by health care workers and 31% indicated it was explained very well. Fifty-four percent were of the opinion that they were included in decision making, with 13% feeling very good about their involvement in decision making. With regard to overall satisfaction of services in the area that the patients lived, 62% were satisfied, while 7% were very dissatisfied with what was available.

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Table 2. *Care provision and satisfaction with health care services*

Variables	**N=55**	**%**
Care providers visited in past 12 months		
Primary Physician/General practitioner	34	63
Rehabilitation Physician/Spinal cord injury Physician	8	14
Other specialist Physician	2	4
Nurse or Midwife	22	40
Dentist	2	4
Physiotherapist	11	20
Chiropractor	1	2
Occupational Therapist	5	9
Psychologist	1	2
Alternative Medicine Practitioner	3	5
Pharmacist	5	9
Home health care worker	3	5
Other	2	4
Did not visit health care provider in past 12 months	7	13
Admissions to any health care facility in past 12 months		
No	47	85
Yes	8	15
In past 12 months, did you need health care, but could not get it?		
No	38	69
Yes	17	31
Reasons for not getting needed health care		
Not affordable	9	16
No service available	1	2
Transport	7	13
Previous bad experience	3	5
Unable to take off time/other commitment	1	2
Health care denied	1	2
Thought you not sick enough	2	4
Other	36	65
Treated respectfully		
Yes	48	87
No	7	13
Information explained by health care workers		
Good	43	78
Neither good nor bad	8	15
Bad	4	7
Involved in decision making		
Good	43	78
Neither good nor bad	7	13
Bad	5	9
How satisfied are you with services in area		
Satisfied	34	62
Dissatisfied	17	31

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4.3 Self–care activities (activity limitations) four years after TSCI

Self-care activities were self-rated using the SCIM III subscale. In Table 3, 73% of the cohort indicated that they were able to eat and drink independently. Adaptive devices and assistance was required by 15% of the participants in order to empower them to eat and drink. In response to bathing of the upper body, 65% of the cohort was able to bath with total independence, while 58% could bath their lower body without the use of adaptive devices. Concerning dressing the upper body, 60% were independent, while 55% were independent with dressing the lower body. Twenty-two percent required total assistance with dressing. Seventy-six percent of the cohort were able to groom themselves independently.


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Table 3. *Self-care activities four years after TSCI*

Variables	**N=55**	**%**
Feeding		
Parental, gastrostomy or fully assisted	4	7
Partial assistance for eating or drinking	3	5
Eats independently, use adaptive devices or some assistance	8	15
Eats and drinks independently	40	73
Bathing Upper body		
Requires total assistance	12	22
Requires partial assistance	3	5
Wash independently with adaptive devices or in specific setting	4	7
Wash independently without adaptive devices or in specific setting	36	65
Bathing Lower Body		
Requires total assistance	12	22
Requires partial assistance	5	9
Wash independently with adaptive devices or in specific setting	6	11
Wash independently without adaptive devices or in specific setting	32	58
Dressing Upper Body		
Requires total assistance	9	16
Requires partial assistance with clothes without buttons and zippers and laces	3	5
Independent. Requires adaptive devices or specific setting	3	5
Independent. No adaptive devices required	7	13
Dresses independently, no assistive devices required	33	60
Dressing Lower body		
Requires total assistance	12	22
Requires partial assistance with clothes without buttons and zippers and laces	4	7
Independent. Requires adaptive devices or specific setting	3	5
Independent. No adaptive devices required	6	11
Dresses independently, no assistive devices required	30	5
Grooming		
Total assistance required	3	5
Requires partial assistance	6	11
Grooms independently with adaptive devices	4	7
Grooms independent without adaptive devices	42	76

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4.4 Activities related to mobility four years after TSCI

The results pertaining to activities related to mobility are indicated in Table 4. Within a scaled rating: without any difficulty, with a little difficulty, with some difficulty, with much difficulty and unable to, 31% of the cohort indicated that they could get from the floor from lying on their back without any difficulty, and 29% were unable to get up from this position. To push open a heavy door, 33% of the participants had no difficulty, while 20% had much difficulty. Sixty-two percent of participatns could move from sitting on the side of the bed to lying on their back without any difficulty.

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Table 4. *Activities related to mobility four years after TSCI*

Variable	N=55	%
Are you able to sit unsupported?		
No	14	25
Yes	40	73
Missing	1	2
Are you able to stand unsupported?		
No	25	45
Yes	27	49
Missing	3	5
Are you able to get up from the floor from lying on your back?		
Without any difficulty	17	31
With a little difficulty	8	15
With some difficulty	8	15
With much difficulty	6	10
Unable to	16	29
Are you able to push open a heavy door?		
Without any difficulty	18	33
With a little difficulty	10	18
With some difficulty	10	18
With much difficulty	11	20
Unable to	6	11
Are you able to move from sitting at the side of the bed to lying down on your back?		
Without any difficulty	34	62
With a little difficulty	7	13
With some difficulty	2	4
With much difficulty	4	6
Unable to	8	15

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4.5 Participation restrictions four years after TSCI

An indication given whether there was no problem, slight problem, moderate problem, severe problem or extreme problem with participation four years after TSCI is captured in Table 5. With carrying out daily routine, 56% of the participants had no problem. The majority, 54.5% of the participants, had no problem in handling stress on a daily basis. Sixty-two percent of the cohort had no problem to use their hands and fingers. Furthermore, 55% of the participants had no problem getting to where they want to go and 56% had no problem using public transport.

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On the contrary, 21.8% had extreme problems using public transport. With regard to private transportation, 55% of the cohort had no problem, where 18% had an extreme problem. The majority of the cohort had no problem with looking after their own health needs (58%), getting household tasks done (56%), providing care or support for others (62%), interacting with others (73%), intimate relationships (65%), doing things for relaxation or pleasure (73%), or shortness of breath during physical activity (65%).

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Table 5. *Participation restrictions four years after TSCI*

Total (n, %)	**55**	**100**
Do you have a problem with:		
Carrying out daily routine		
No problem	31	56
Slight problem	10	18
Moderate problem	8	15
Severe problem	1	2
Extreme problem	5	9
Handling Stress		
No problem	30	55
Slight problem	12	22
Moderate problem	3	5
Severe problem	7	13
Extreme problem	3	5
Using your hands and fingers		
No problem	34	62
Slight problem	5	9
Moderate problem	6	11
Severe problem	5	9
Extreme problem	5	9
Getting where you want to go		
No problem	30	54
Slight problem	6	11
Moderate problem	5	9
Severe problem	6	11
Extreme problem	8	15
Using public transportation		
No problem	31	56
Slight problem	2	4
Moderate problem	7	13
Severe problem	3	5
Extreme problem	12	22
Using private transportation		
No problem	30	55
Slight problem	5	9
Moderate problem	6	11
Severe problem	4	7
Extreme problem	10	18
Looking after your health needs		
No problem	32	58
Slight problem	9	16
Moderate problem	9	16
Severe problem	1	2
Extreme problem	4	7

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Getting household tasks done		
No problem	31	56
Slight problem	5	9
Moderate problem	3	6
Severe problem	6	11
Extreme problem	10	18
Provide care or support for others		
No problem	34	62
Slight problem	3	5
Moderate problem	6	11
Severe problem	4	7
Extreme problem	8	15
Interacting with others		
No problem	40	73
Slight problem	6	11
Moderate problem	3	5
Severe problem	1	2
Extreme problem	5	9
With intimate relationships		
No problem	36	65
Slight problem	4	7
Moderate problem	2	4
Severe problem	6	11
Extreme problem	7	13
Doing things for relaxation or pleasure		
No problem	40	73
Slight problem	2	4
Moderate problem	4	6
Severe problem	2	4
Extreme problem	7	13
Shortness of breath during physical exertion		
No problem	36	65
Slight problem	7	13
Moderate problem	5	9
Severe problem	3	5
Extreme problem	4	7

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4.6 Participation in work, vocational rehabilitation and disability pension four years after TSCI

The results in Table 6 show that 60% of the cohort did not receive vocational rehabilitative services after their SCI injury. Furthermore, 56% of the cohort received some form of pension or disability benefit. The bulk of 73% of the cohort did not engaged in paid work, considering that they are at an employable age.

Table 6. *Participation at work,vocational rehabilitation and disability pension four years after TSCI*

Variables	**N=55**	**%**
Did you receive vocational rehabilitation services after your spinal cord injury?		
Yes	17	31
No	38	60
Do you receive disability pension or similar disability benefit?		
Yes	31	56
No	24	44
Are you currently engaged in paid work?		
Yes	12	22
No	40	73
Missing	3	5

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4.7 Factors associated with activity

4.7.1 Univariate analysis

As indicated in Table 7, both contextual and injury-related factors were considered in the prediction of activity, i.e. self-care according to the SCIM-SR subscale. On a univariate level, gender, as a personal factor, was found to be related to self-care, as well as level of injury, as a characteristic of body function. Specifically, females demonstrated significantly higher (*P*=0.04) self-care abilities than males. Also, those with tetraplegia experienced significantly (*P*=0.02) more problems with self-care than individuals with paraplegia.

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Table 7. *Univariate analysis of factors associated with self-care according to SCIM-SR*

Variables	**β[a] (t)**	***P***	**95% *CI***
Personal factors			
Age (years)	-0.04 (-0.57)	0.57	-0.18 ─ 0.10
Gender (male/female)	5.14 (2.10)	**0.04**	0.22 ─ 10.05
Living alone (Alone/ with others)	-3.54 (-1.68)	0.09	-7.77 ─ 0.69
Employed (paid work)	-2.75 (-1.20)	0.24	-7.37 ─ 1.90
Environmental factor			
Healthcare services received as needed	-2.53 (-1.26)	0.21	-6.57 ─ 1.50
Body structure and functions			
Level of injury (paraplegia vs. tetraplegia)	-5.03 (-2.48)	**0.02**	-9.12 ─ -0.95
Severity (complete vs. incomplete)	-0.20 (-0.09)	0.93	-4.78 ─ 4.38

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4.7.2 Factors associated with activity – multivariate analysis

Those factors with a *P* value equal or less to 0.15, as found in the univariate analysis, were considered in the multivariate analysis of independently associated factors. As seen in Table 8, the final model contained the following variables: gender, living arrangement, and level of injury. However, only level of injury was found to be independently associated with self-care (activity) after controlling for the remaining factors in the model. This final model only explains 15% of the variance in self-care scores in the sample.

Table 8. *Multivariable model of factors associated with self-care per SCIM-SR*

Variables	**β[a] (t)**	***P***	**95% *CI***
Gender	3.74 (1.33)	0.20	-1.93 ─ 9.41
Living alone (alone/with others)	-3.70 (-1.73)	0.09	-7.99 ─ 0.60
Level of injury	-4.39 (-2.12)	**0.04**	-8.56 ─ -0.22

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4.8 Factors associated with participation in paid work four years after TSCI

Similar to the prediction of self-care, contextual and injury-related factors were considered. For this outcome (i.e. engaged in paid work at four years after injury), binary logistic regression analysis was carried out. None of the personal (i.e. gender, age, and living arrangement), contextual, and injury-related factors were found to be associated with engagement in paid work at four years after injury. Table 9 illustrates the univariate logistic regression analysis.

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Table 9. *Factors associated with paid work four years after TSCI*

Variables	***OR* (95%CI)**	***P-value***
Personal factors		
Gender		0.88
Female	0.88 (0.15-5.07)	
Male	1.00(reference)	
Age (continuous)	0.98 (0.94-1.04)	0.62
Living arrangement		
Living alone	1.00 (reference)	0.45
Living with partner	0.58 (0.14-2.38)	
Contextual factor		
Healthcare services received as needed		0.08
No	1.00 (reference)	
Yes	6.6 (0.78-56.37)	
Body function and activity		
Level of injury		0.33
Tetraplegia	0.5 (0.12-2.07)	
Paraplegia	1.00 (reference)	
Completeness of injury		0.86
Incomplete	1.00 (reference)	
Complete	1.15 (0.25-5.16)	
Self-care SCIM-SR (continuous)	0.94 (0.84-1.05)	0.77

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Chapter 5

Discussion

This chapter discusses the most striking results from this study, which was aimed at investigating activity and participation in persons with TSCI. This chapter provides the reader with a deeper understanding of the results pertaining to healthcare services and activity limitations and participation restrictions four years after TSCI by comparing the functioning status to other SCI populations in the world. In addition, this chapter discusses the findings in the light of the conceptual model used in this study, i.e. the ICF.

5.1 Description of the study findings – socio-demographic and injury characteristics

In this study, 84% of the cohort were males, and the mean age of the cohort was 36 years. This indicates that it is the working force of the communities who is largely affected by this injury. Furthermore, the primary cause of TSCI in this cohort is assault (53%), followed by transport (38%).

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The demographic profile of participants included in this study is significantly different from other cohorts in the world, especially those from developed contexts where individuals are often older and where the leading cause of injury is falls or transport related (Chiu et al., 2010). The unique profile of persons with TSCI in South Africa, in terms of age, gender and aetiology, requires investigation in terms of health care usage and satisfaction of care received in order to determine whether services are relevant to this cohort. Furthermore understanding the lived experiences, in terms of activity and participation, of this population is vital in order to inform the development and implementation of targeted rehabilitation interventions.

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5.2 Health care services and satisfaction

Research shows that majority of citizens make use of non-specialized services due to the lack of specialised care within the communities (Joseph et al., 2017; Joseph et al., 2015; Phillips, Braaf & Joseph, 2018). The results of this study found that a general practitioner or primary physician was consulted more often than any other professionals (63%), whereas rehabilitation personnel such as physiotherapists were consulted by 20% of the cohort and an occupational therapist by 9% of the participants in the last 12 months. In the Netherlands, similar results were found, where the general practitioner was the first medical contact after secondary complications for SCI (Van Loo, Post, Bloemen & Van Asbeck, 2010). During the past 12 months, 31% were in need of health care, but was unable to access it. Seventeen percent could not access health care due to the lack of funds and 13% because of transport challenges. Those who accessed health care services had a satisfaction rate of 62%.

The role of community-based rehabilitation, delivered on an out-patient basis, is the promotion of functional independence and participation in society. This is of particular importance due to the younger age of injury onset in this cohort, where people are still at an employable age. Furthermore, the promotion of functional recovery is of particular importance to this cohort since predominantly men, who are often the primary breadwinner, are injured. This may pose a considerable burden on the family and children, as well as on society as a whole. Given the challenges with mobility and employment in this cohort, access to rehabilitation services such as physiotherapy and occupational therapy seems to be lacking, as reflected in the percentage of persons utilising those services the past 12 months. The belief is that primarily, rehabilitation during the acute stages of SCI is effective. Resent research shows that ongoing rehabilitation during the chronic stages of SCI assist in management of impaired functions, and ultimately improves the quality of life (Yadav, Kumar & Khan, 2018). It is therefore important that rehabilitation within the community be accessed on a regular basis to improve mobility, reduce secondary complications and improve the quality of life.

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The results of this study demonstrated that approximately one-third of the cohort was dissatisfied with health care services in their area of residence. Clients' satisfaction with healthcare services is an important distal outcome, and provides evidence for their perceptions concerning their recovery and participation. This study provides the basis for further exploring why persons with TSCI are dissatisfied with services. The information could thus inform the development of care systems which specifically target clients' needs.

5.3 Activity four years after injury

When looking at activities such as feeding, bathing the upper and lower body, dressing the upper and lower body and grooming, most participants in this study were able to perform these activities independently. With both bathing the upper and lower body, total assistance was needed by 22% of the participants. With grooming, 11% needed some sort of assistive device to help them. Similar results was recorded in studies by Joseph et al. (2013) and Maclachlan (2014). However, the follow up period after injury onset differed between studies, with the latter studies collecting functional data six months post injury. A study in the United States of America showed that tetraplegic patients consider regaining hand and arm function as their primary need. In the same study, paraplegic patients had sexual function as their primary need (Anderson, 2004). Concerning mobility, a large percentage of the cohort were not able to stand independently. Maclachlan (2014) showed that, post discharge, a number of individuals need assistance with standing, and ongoing rehabilitation is therefore required.

5.4 Participation four years after injury

Participation with daily tasks was perceived to not be a problem by 56% of participants. Research proves that participation improves post discharge from in-patient rehabilitation (Maclachlan, 2014). This could be attributed to the fact that the longer you are within an environment, the more you will adapt to it. A small percentage of the cohort had difficulty with household task and looking after their own needs. Transportation is a challenge, especially for

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those who need to make use of public transport. This was found to be true in a study by Joseph et al. (2016). Here in this study, individuals could not participate due to the lack of adequate transportation.

The role of community health-care services is to train individuals with SCIs towards functional independence, to promote participation within the environment and to facilitate return to work. With only a few people accessing physiotherapy and occupational therapy within the community, this process of rehabilitation is not followed through. Furthermore, thirty-eight participants (60%) did not receive vocational rehabilitation. Vocational rehabilitation restores or develops the ability of the individual to compete and play a role in the labour market. The lack of vocational rehabilitation is a barrier to employment (WHO, 2011). Unemployment in the population of working age disabled persons is significantly lower than those who are not disabled; the lack of access to education and vocational rehabilitation plays a role in this (WHO, 2011).

In Germany, after SCI injury there was an unemployment rate of 59% (Anneken, Hanssen-Doose, Hirschfeld, Scheuer & Thietje, 2010). The 56% of participants who receive a pension or grant in this study is a reflection of the degree of unemployment amongst individuals with SCI in South Africa. Although participation was not seen as a restriction by many of the cohort, 73% were unemployed.

5.5 Factors related to activity and participation (work)

Within the study, females had a higher self-care ability than males. It is possible that females are more motivated than males since they are usually responsible for the care of others within their home. This is especially true within the South African context where care of your parents is the daughter's responsibility. Individuals with paraplegia were also less likely to have difficulties with self-care compared to individuals with tetraplegia. This is due to the level of injury, where people with paraplegia have fewer muscles that are affected by the injury (Hicks

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et al., 2003). Therefore, more adaptive tools should be made available to enhance functional independence.

Concerning return-to-work, no factors were found to be related. This could be due to the small sample size, of 55, leading to the lack of statistical power. Alternatively, other important factors, such as motivation, self-efficacy, and previous occupation, central to regaining entry into the labour market have not been included. Although there are studies which link higher education with higher rate of return to work (Schonher, Groothoff, Mulder, Schoppen & Eisma, 2004), in a study by Suttiwong et al. (2015), of the 80% employed, only 35% were college graduates.

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Chapter 6

Conclusion, study limitations and recommendations

6.1 Conclusion

In relation to objective one, it was found that males, who are most likely to be the primary breadwinners, sustained TSCI predominantly by assault (53%) over and above any other cause.

Pertaining to objective 2, those who accessed healthcare services mostly made use of general practitioners and primary physicians. Although rehabilitation is done at community level, by physiotherapists and occupational therapists (Kahonde et al., 2010), a small percentage of the cohort made use of these services. Health care was not accessible to 31% of the cohort, this results in even less people accessing therapy. Those who accessed health care were generally satisfied with the respect that they received, explanations provided by health care professional, involvement in decision-making and the services in their residential area.

Activity limitations was bathing of the upper and lower body, as well as dressing the lower body. Due to the challenge in accessing services and not receiving post discharge rehabilitation, these limitations were possibly not addressed in therapy. Another restriction, regarding mobility is getting up from lying on your back on the floor. This is a skill that could be taught during long term rehabilitation. As per participation restriction, using public transportation was the most common participation restriction, and the use of private transportation follows this restriction.

Level of injury (paraplegia versus. paraplegia), was the only independent factor related to self-care activity. More assistance and options for adaptive tools should be provided to those with tetraplegia with the aim of facilitating improved functional ability. Pertaining to the participation restrictions, when looking at participation at work, most of the participants did not

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receive vocational rehabilitation. Twenty-two percent are involved in paid work, and 56% receives some form of disability benefit or grant.

6.2 Study limitations

- This study was done in the public sector and excluded private patients. The private sector typically has access to a more efficient referral system as well a better distribution of rehabilitation services.

- A number of patients have passed on within the past four years post TSCI of the cohort. The cause of death could have been indirectly related to activity limitations or participation restrictions. Understanding the relationship between activity-participation and mortality is important for promoting specialised services along the continuum of the disease progression.

- Many patients could not be found due to the change in address, and or telephone numbers. Since many of the patients lived in dangerous areas, it was a challenge to get to them. This resulted in a smaller sample size and this could have implication on the study results and the generalizability thereof.

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- Some questionnaires had missing data. The Questionnaire is an extensive document with 125 items included. However, we only included data sets with at least 80% completion. We did not explore the missingness mechanisms.

- Activity limitations and participation restrictions were subjective and self-reported based on perceived and not actual performance.

- This study was a cross-sectional study and not a longitudinal, observational study; therefore, causality cannot be established in terms of factors related to activity limitations and participation restrictions.

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- Pre- injury work status information was not collected during this study, therefore no comparison could be made.

- There is the potential for recall bias for the participants who has difficulty to recall information about variables of the past 12 months.

6.3 Recommendations

Based on this study and its limitations, recommendations for future studies would be:

- Include both public and private sector in the sample size in order to gain a better reflection of satisfaction of health services as well as long-term rehabilitation accessed.

- Research can be done within a shorter time after injury, and followed up at four years, in order to assess whether time since injury result in different limitations and restrictions. This information could thus be used to provide timeous access to needed intervention and services.

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- Participants in dangerous areas could be contacted, and asked to meet outside of the areas, or law enforcement could assist going into the areas in order to enhance the response rate.

- Questionnaires could be completed over two or three sessions so that participants have more time to reflect upon it.

- A brief assessment of participant's activity limitation could be conducted. This will also give more insight into participation restrictions as well as underlying reason for the activity limitation.

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References

Anderson, C., Vogel, L., Willis, K., & Betz, R. (2006). Stability of transition to adulthood among individuals with pediatric-onset spinal cord injuries. *The Journal of Spinal Cord Medicine and Rehabilitation*, *29*(1), 46–56. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1864785/pdf/i1079-0268-29-1-46.pdf

Anderson, K. (2004). Targeting recovery: Priorities of the spinal cord-injured population. *Journal of Neurotrauma*, *21*(10), 1371–1383. doi: 10.1089/neu.2004.21.1371

Anneken, V., Hanssen-Doose, A., Hirschfeld, S., Scheuer, T., & Thietje, R. (2010). Influence of physical exercise on quality of life in individuals with spinal cord injury. *Spinal Cord*, *48*(5), 393–399. doi:10.1038/sc.2009.137

Ballert, C., Post, M., Brinkhof, M. W., Reinhardt, J. D., & Group, S. S. (2015). Psychometric properties of the nottwil environmental factors inventory short form. *Arch Ives of Physycal Medicine and Rehabilitation*, *96*(2), 233–40. Retrieved from https://www.nature.com/sc/journal/v49/n2/pdf/sc2010111a.p

Beauregard, L., Guidon, A., Noreau, L., Lefebvre, H., & Boucher, N. (2012). Community needs of people living with spinal cord injury and their family. *Topics in Spinal Cord Injury Rehabilitation*, *18*(2), 122–125. doi:10.1310/sci1802-122

Catz, A., Itzkovich, M., Agranov, E., Ring, H., & Tamir, A. (1997). SCIM - spinal cord independence measure : a new disability scale for patients with spinal cord lesions. *Spinal Cord*, *35*, 850–856. doi:10.1007/978-0-387-79948-3_1848

Chamberlain, J., Meier, S., Mader, L., Von Groote, P., & Brinkhof, M. (2015). Mortality and longevity after a spinal cord injury: Systematic review and meta-analysis. *Neuroepidemiology*, *44*(3), 182–198. doi:10.1159/000382079

Chiu, W., Lin, H., Lam, C., Chu, S., Chiang, Y., & Tsai, S. (2010). Review paper:

UNIVERSITY of the WESTERN CAPE

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

epidemiology of traumatic spinal cord injury: comparisons between developed and developing countries. *Asia-Pacific Journal of Public Health*, *22*(1), 9–18.

Department of health. (2016). *Framework and strategy for disability and rehabilitation services in South Africa 2015-2020.* Retreived from www.ilifalabantwana.co.za/wp-content/uploads/2016/07/Framework-25-may_1_3.docx

Dijkers, M. (2005). Quality of life of individuals with spinal cord injury: A review of conceptualization, measurement, and research findings. *The Journal of Rehabilitation Research and Development*, *42*(3), 87. doi:10.1682/JRRD.2004.08.0100

Fekete, C., Eriks-Hoogland, I., Baumberger, M., Catz, A., Itzkovich, M., Luthi, H., … Brinkhof, M. (2013). Development and validation of a self-report version of the Spinal Cord Independence Measure (SCIM III). *Spinal Cord*, 40–47. doi:10.1038/sc.2012.87

Furlan, J., Noonan, V., Cadotte, D., & Fehlings, M. (2011). Timing of decompressive surgery of spinal cord after traumatic spinal cord injury : An evidence-based examination of pre-clinical and clinical studies. *Journal of Neurotrauma*, *28*(8), 1371–1399.

Hagen, E. M. (2015). Acute complications of spinal cord injuries. *World Journal of Orthopedics*, *6*(1), 17–23. doi:10.5312/wjo.v6.i1.17

Hicks, A., Martin, K., Ditor, D., Latimer, A., Craven, C., Bugaresti, J., & McCartney, N. (2003). Long-term exercise training in persons with spinal cord injury: Effects on strength, arm ergometry performance and psychological well-being. *Spinal Cord*, *41*(1), 34–43. doi:10.1038/sj.sc.3101389

Jazayeri, S., Beygi, S., Shokraneh, F., Hagen, E., & Rahimi-Movaghar, V. (2015). Incidence of traumatic spinal cord injury worldwide: a systematic review. *European Spine Journal*, *24*(5), 905–918. doi:10.1007/s00586-014-3424-6

Jette, D., Halbert, J., Iverson, C., Miceli, E., & Shah, P. (2016). Use of standardized outcome

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

measures in physical therapist practice : Perceptions and application. *Physical Therapy*, *89*(2), 125–135. doi:10.2522/ptj.20080234

Joseph, C. (2016). Traumatic Spinal Cord Injury in South Africa and Sweden: Epidemiologic features and functioning (Doctoral dissertation, Karolinska Institutet, Stockholm, Sweden). Retrieved from https://openarchive.ki.se/xmlui/bitstream/handle/10616/45096/Thesis_Conran_Joseph.pdf?sequence=1

Joseph, C., Andersson, N., Bjelak, S., Giesecke, K., Hultling, C., Nilsson-Wikmar, L., … Wahman, K. (2017). Incidence, aetiology and injury characteristics of traumatic spinal cord injury in stockholm, sweden: A prospective, population-based update. *Journal of Rehabilitation Medicine*, *49*, 431–436. doi:10.2340/16501977-2224

Joseph, C., Delcarme, A., Vlok, I., Wahman, K., Phillips, J., & Nilsson-Wikmar, L. (2015). Incidence and aetiology of traumatic spinal cord injury in Cape Town , South Africa : a prospective , population-based study. *Spinal Cord*, *53*(9), 692–696. doi:10.1038/sc.2015.51

UNIVERSITY of the
WESTERN CAPE

Joseph, C., Mji, G., Statham, S., Mlenzana, N., De Wet, C., & Rhoda, A. (2013). Changes in activity limitations and predictors of functional outcome of patients with spinal cord injury following in-patient rehabilitation. *South African Journal of Physiotherapy*, *69*(1), 41–49. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=cin20&AN=108008550&lang=ja&site=ehost-live

Joseph, C., & Nilsson-Wikmar, L. N. (2016). Prevalence of secondary medical complications and risk factors for pressure ulcers after traumatic spinal cord injury during acute care in South Africa. *Spinal Cord*, *54*(7), 535–539. doi:10.1038/sc.2015.189

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

Joseph, C., Scriba, E., Wilson, V., Mothabeng, J., & Theron, F. (2017). People with spinal cord injury in republic of South Africa. *American Journal of Physical Medicine & Rehabilitation, 96*(2), 109–111. doi:10.1097/PHM.0000000000000594

Joseph, C., Wahman, K., Phillips, J., & Nilsson-Wikmar, L. (2016). Client perspectives on reclaiming participation after a traumatic spinal cord injury in South Africa. *Physical Therapy, 96*(9), 1372–1380. doi:10.2522/ptj.20150258

Kahonde, C., Mlenzana, N., & Rhoda, A. (2010). Persons with physical disabilities ' experiences of rehabilitation services at Community Health Centres in Cape Town . *South African Journal of Physiotherapy, 66*(3). Retrieved from https://www.sajp.co.za/index.php/sajp/article/viewFile/67/64

Kawanishi, C., & Greguol, M. (2013). Physical activity, quality of life, and functional autonomy of adults with spinal cord injuries. *Adapted Physical Activity Quarterly, 30*, 317–337. doi:10.1038/sc.2009.137

Kirchberger, I., Cieza, A., Biering-Sørensen, F., Baumberger, M., Charlifue, S., Post, M. W., ... & Kostanjsek, N. (2010). ICF Core Sets for individuals with spinal cord injury in the early post-acute context. *Spinal cord, 48*(4), 297.

Linacre, J., Heinemann, A., Wright, B., Granger, C., & Hamilton, B. (1994). The structure and stability of the Functional Independence Measure. *Archives of physical medicine and rehabilitation, 75*(2), 127-132. Retrieved from https://www.archives-pmr.org/article/0003-9993(94)90384-0/pdf

Löfvenmark, I. (2016). Epidemiology , Outcomes and Experiences of Living With Traumatic Spinal Cord Injury in Botswana (Doctoral disseration, Karolinska Institutet, Stockholm, Sweden). Retrieved from https://openarchive.ki.se/xmlui/bitstream/handle/10616/45253/Thesis_Inka_Löfvenmark.

UNIVERSITY of the WESTERN CAPE

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

pdf?sequence=1&isAllowed=y

Löfvenmark, I., Norrbrink, C., Nilsson-Wikmar, L., Hultling, C., Chakandinakira, S., & Hasselberg, M. (2015). Traumatic spinal cord injury in Botswana : Characteristics , aetiology and mortality. *Spinal Cord*, *53*(2), 150–154. doi:10.1038/sc.2014.203

Maclachlan, M. (2014). The activity and participation profile of persons with traumatic spinal cord injury in the Cape Metropole, Western Cape, South Africa: A prospective, descriptive study. *Gait & Posture*, *13*(April), 145–149. doi:10.1093/fampra/13.6.522

Munce, S., Fehlings, M., Straus, S., Nugaeva, N., Jang, E., Webster, F., & Jaglal, S. (2014). Views of people with traumatic spinal cord injury about the components of self-management programs and program delivery: a Canadian pilot study. *BMC Neurology*, *14*(1), 209. doi:10.1186/s12883-014-0209-9

Nas, K., Yazmalar, L., Şah, V., Aydın, A., & Öneş, K. (2015). Rehabilitation of spinal cord injuries. *World Journal of Orthopedics*, *6*(1), 8–16. doi:10.5312/wjo.v6.i1.8

Olckers, M. (2017). The factors influencing community reintegration of traumatic spinal cord injury patients in a South African population (Masters dissertation, Univeristy of Western Cape, Cape Town, South Africa). Retrieved from http://etd.uwc.ac.za/handle/11394/5783

Pefile, N., Mothabeng, J., & Naidoo, S. (2018). Profile of patients with spinal cord injuries in Kwazulu-Natal, South Africa: Implicactions for vocational rehabilitation. *Journal of Spinal Cord Medicine*. doi:10.1080/10790268.2018.1428264

Phillips, J., Braaf, J., & Joseph, C. (2018). Another piece to the epidemiological puzzle of traumatic spinal cord injury in Cape Town, South Africa: A population-based study. *South African Medical Journal*, *108*(12). doi:10.7196/SAMJ.2018.v108i12.13134

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

Post, M., Dallmeijer, A., Angenot, E., van Asbeck, F., & van der Woude, L. (2005). Duration and functional outcome of spinal cord injury rehabilitation in the Netherlands. *Journal of Rehabilitation Research and Development*, *42*(3), 75–85. doi:10.1682/JRRD.2004.10.0133

Rahimi-Movaghar, V., Sayyah, M., Khorramirouz, R., Rasouli, M., Moradi-Lakeh, M., Shokraneh, F., & Vaccaro, A. (2013). Epidemiology of traumatic spinal cord injury in developing countries : a systematic review. *Neuro Epidemiology*, *41*(2), 65–85. doi:10.1159/000350710

Saurez, N., Levi, R., & Bullington, J. (2013). Regaining health and wellbeing after traumatic spinal cord injury. *Journal of Rehabilitation Medicine*, *45*(10), 1023–7. doi:10.2340/16501977-1226

Savic, G., Devivo, M., Frankel, H., Jamous, M., Soni, B., & Charlifue, S. (2017). Causes of death after traumatic spinal cord injury - a 70-year British study. *Spinal Cord*, *55*(10), 891–897. doi:10.1038/sc.2017.64

Schonher, M., Groothoff, G., Mulder, G., Schoppen, T., & Eisma, W. (2004). Vocational reintegration following spinal cord injury: expectations, participation and interventions. *Spinal Cord*, (42), 177–184.

Schottmüller, H. (2007). *Survey Documentation*. Retrieved from https://www.ilias.de/docu/goto_docu_file_949_download.html

Sothmann, J., Stander, J., Kruger, N., & Dunn, R. (2015). Epidemiology of acute spinal cord injuries in the Groote Schuur hospital acute spinal cord injury (GSH ASCI) unit, Cape Town, South Africa, over the past 11 years. *South African Medical Journal*, *105*(10), 835–839. doi:10.7196/SAMJnew.8072

Suttiwong., J., Vongsirinavarat, M., Chaiyawat, P., & Vachalathiti, R. (2015). Predicting

UNIVERSITY of the WESTERN CAPE

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

community participation after spinal cord injury in Thailand. *Journal of Rehabilitation Medicine*, *47*(4), 325–329. doi:10.2340/16501977-1932

Swiss Spinal Cord Cohort Study. (n.d.). Retrieved September 29, 2017, from https://www.swisci.ch/en

Trani, J., Babulal, G. M., & Bakhshi, P. (2015). Development and Validation of the 34-Item Disability Screening Questionnaire (DSQ-34) for Use in Low and Middle Income Countries Epidemiological and Development Surveys. *PLoS ONE*, *10*(12), 1–14. doi:10.1371/journal.pone.0143610

Van Loo, M. A., Post, M. W. M., Bloemen, J. H. A., & Van Asbeck, F. W. A. (2010). Care needs of persons with long-term spinal cord injury living at home in the Netherlands. *Spinal Cord*, *48*(5), 423–428. doi:10.1038/sc.2009.142

Vissers, M., van den Berg-Emons, R., Sluis, T., Bergen, M., Stam, H., & Bussmann, H. (2008). Barriers to and facilitators of everyday physical activity in persons with a spinal cord injury after discharge from the rehabilitation centre. *Journal of Rehabilitation Medicine*, *40*(6), 461–467. doi:10.2340/16501977-0191

UNIVERSITY of the WESTERN CAPE

Whiteneck, G., Tate, D., & Charlifue, S. (1999). Predicting community reintegration after spinal cord injury from demographic and injury characteristics. *Archives of Physical Medicine and Rehabilitation*, *80*(11), 1485–91. Retrieved from http://www.archives-pmr.org/article/S0003-9993%2899%2990262-9/pdf

Wing, P. (2008). Early acute management in adults with pinal cord injury: A clinical practice guideline for health-care providers. Who should read it? *The Journal of Spinal Cord Mediciner*, *31*(4), 403–479. Retrieved from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2582434/pdf/i1079-0268-31-4-408.pdf

Wirth, B., van Hedel, H., Kometer, B., Dietz, V., & Curt, A. (2008). Changes in activity after

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

a complete spinal cord injury as measured by the Spinal Cord Independence Measure II (SCIM II). *Neuralrehabilitation and Neural Repair*, *22*(2), 145–153. Retrieved from http://www.zora.uzh.ch/id/eprint/3268/

World Health Organization. (2002). Towards a Common Language for Functioning , Disability and Health ICF. *International Classification*, *1149*, 1–22. doi:WHO/EIP/GPE/CAS/01.3

World Health Organization. (2011). World report on disability 2011. *American Journal of Physical Medicine Rehabilitation Association of Academic Physiciatrists*, *91*, 549. doi:10.1136/ip.2007.018143

World Health Organization. (2015). *Model Disability Survey : Providing evidence for accountability and decision-making*. Retrieved from http://www.who.int/disabilities/data/mds_v4.pdf?ua=1

World Health Organization & International Spinal Cord Society. (2013). *International perspective on spinal cord injury*. World Health Organisation. Retrieved from http://www.who.int/mediacentre/factsheets/fs384/en/

Yadav, R., Kumar, S., & Khan, S. (2018). Chronic spinal cord injury : A life changer , a disease process rather than an event and its rehabilitation. *International Journal of Yogic, Human Movement and Sports Sciences*, (September). Retrieved from https://www.researchgate.net/publication/327592371_Chronic_spinal_cord_injury_A_life_changer_a_disease_process_rather_than_an_event_and_its_rehabilitation

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Appendices

Appendix A: International Spinal Cord Injury Survey - English

International Spinal Cord Injury Survey (InSCI)

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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

ISPRM International Society of Physical and Rehabilitation Medicine

World Health Organization

ISCOS The International Spinal Cord Society

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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 (InSCI-ID) and there is no personal information such as name or address on the paper or online questionnaire.

In case you have any question or need support in questionnaire completion, we are happy to help. Please send us an email at contact@en.insci.network 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

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Personal information

1. **Please indicate your gender:**
   - ○ Male
   - ○ Female

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

   DD / MM / YYYY

   □□/□□/□□□□

3. **In which country were you born?**

   ✎.....

4. **What is your current marital status?**
   - ○ Single
   - ○ Married
   - ○ Cohabiting or in a partnership
   - ○ Separated or divorced
   - ○ Widowed

5. **Who lives in your household with you?**

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

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6. **Do you get assistance with your day-to-day activities at home or outside?**
   - ○ No
   - ○ Yes, by the following persons:

     Check all that apply
     - ☐ Family
     - ☐ Friends
     - ☐ Professionals or paid assistants

7. **What is the highest level of education that you have completed?**
   - ○ Primary
   - ○ Lower secondary
   - ○ Higher secondary
   - ○ Post-secondary
   - ○ Short tertiary
   - ○ Bachelor or equivalent
   - ○ Master or equivalent
   - ○ Other, namely: ✎ .....

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

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

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

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

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

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

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

Where would you place yourself on this ladder?

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

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

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

Caused by injury:

Check all that apply

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

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

Caused by disease:

Check all that apply

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

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

DD / MM / YYYY

☐☐/☐☐/☐☐☐☐

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Energy and feelings

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

How much of the time during the 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

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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 close to a heater or fire.*	○	○	○	○	○	○ Yes ○ No
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

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

No pain — *Pain as bad as you can imagine*

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

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

☐ No additional health problem experienced

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✎.....

✎.....

✎.....

✎.....

✎.....

40. Please indicate your current smoking status:

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

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Activity and participation

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

	In the 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 periods such as 30 minutes?	○	○	○	○	○
55.	Are you able to stand unsupported? ○ No	○	○	○	○	○

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○ 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 difficulty*	*Unable to do*
56.	**…get up off the floor from lying on your back?**	○	○	○	○	○
57.	**…push open a heavy door?**	○	○	○	○	○
58.	**…moving from sitting at the side of the bed to lying down on your back?**	○	○	○	○	○

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Independence in activities of daily living

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

59. Eating and drinking

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

60. Washing your upper body and head

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

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

61. Washing your lower body

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

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

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62. Dressing your upper body

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

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

- ○ I need total assistance
- ○ I need partial assistance, even with easy-to-dress clothes
- ○ I do not need assistance with easy-to-dress clothes, but I need adaptive devices or specific equipment
- ○ I am independent with easy-to-dress clothes and only need assistance or adaptive devices or a specific setting with difficult-to-dress clothes
- ○ I am completely independent

63. Dressing your lower body

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

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

- ○ I need total assistance

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- ○ 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

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66. Bowel management

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

- ○ Yes
- ○ No

B. My bowel movements are…

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

C. Fecal incontinence ("accidents") happens …

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

67. Using the toilet

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

- ○ I need total assistance

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

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

Check all that apply

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

69. Transfers from the bed to the wheelchair

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

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

I use a wheelchair. To move around, …

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

I walk moderate distances and I ...

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

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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?

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

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

- ○ Yes
- ○ No

75. What is your current working situation?

Check all that apply

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

76. Are you currently engaged in paid work?

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

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

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

✎ .....

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

- ○ More hours
- ○ Less hours

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○ 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*	○	○	○	○	○

		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*	○	○	○	○	○	○

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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.**	○	○	○	○
83.	**Considering all my efforts and achievements, my salary is adequate.** *→ Please go to question no. 87*	○	○	○	○

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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
- ☐ 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**	○	○	○	○

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	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, 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

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

✎..... *(times)*

	For your last visit to a health care provider, how would you rate the following:	*Very good*	*Good*	*Neither good nor bad*	*Bad*	*Very bad*
103.	**...your experience of being treated respectfully?**	○	○	○	○	○
104.	**...how clearly health care providers explained things to you?**	○	○	○	○	○

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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
- ☐ 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 dissatisfied*
107.	In general, how satisfied are you with how the health care services are run in your area?	○	○	○	○	○

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Personal factors

The following questions are about how you see yourself.

		1 Not at all	*2*	*3*	*4*	*5 Completely*
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?	○	○	○	○	○

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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*	○	○	○	○	○
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?	○	○	○	○	○

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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?	○	○	○	○	○

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		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
- ○ 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

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We thank you very much

for participating in the InSCI survey!

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Appendix B: International Spinal Cord Injury Survey - Afrikaans

International Spinal Cord Injury Survey (InSCI)

Afrikaanse weergawe

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

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

In samewerking met

ISPRM International Society of Physical and Rehabilitation Medicine

World Health Organization

ISCOS The International Spinal Cord Society

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

Beste Deelnemer

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

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

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

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

U InSCI-ID is: ######

U se persoonlike wagwoord is: ######

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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.

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

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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
     - ☐ 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: .....

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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.

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

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

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

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

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

Oorsaak deur besering:

Merk als wat van toepassing is

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

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

Oorsaak a.g.v. siekte:

Merk als wat van toepassing is

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

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

DD / MM / JJJJ

☐☐/☐☐/☐☐☐☐

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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

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32.	**Respiratoriese Probleme (Asemhalingsprobleme)** *Simptome van respiratoriese infeksies of –probleme sluit in moeilikheid met asemhaling en toenemende uitskeidings.*	○	○	○	○	○	○ Ja ○ Nee
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

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

Geen pyn — *Die ergste pyn wat u u kan voorstel*

○ ○ ○ ○ ○ ○ ○ ○ ○ ○ ○

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0 1 2 3 4 5 6 7 8 9 10

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

☐ Geen addisionele gesondheidsprobleme om te verklaar

✎.....

✎.....

✎.....

✎.....

✎.....

40. **Dui asseblief u huidige "rookstatus" aan:**

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

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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 laaste 4 weke, 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 sit? ○ Nee ○ Ja → Hoeveel van 'n probleem is dit om vir lang periodes soos 30 minute te sit?	○	○	○	○	○

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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**?**	○	○	○	○	○

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

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

60. Was van bo-lyf en hoof

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

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

61. Was van onderlyf

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

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

62. Klee (aantrek) van die bolyf

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

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

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

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of ‘n spesifieke omgewing met moeilik- om- aan- te- trek klere.

O Ek is heeltemal onafhanklik.

63. Klee van die onder gedeelte van die liggaam

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

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

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.

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

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65.

Blaashantering

Dink asseblief aan die manier hoe u u blaas verlig.

D. Gebruik van ‘n interne kateter

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

E. Onderbroke katetergebruik

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

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

- ○ Ek benodig algehele bystand
- ○ Ek benodig gedeeltelike bystand
- ○ Ek gebruik dit sonder bystand

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- ○ Ek is selfbeheerst met uriene en gebruik geen dreineringsinstrument nie.

66. Beheer van ontlasting

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

- ○ Ja
- ○ Nee

B. Ek ontlas…

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

C. 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
- ○ 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, …

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

Ek stap gemiddelde distansies en ek...

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

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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

○ 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: ✎ .....

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

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		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 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.*	○	○	○	○	○	○

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

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

○ Ja

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- ○ Nee

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

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

86. Om watter redes werk u tans nie?

Merk als wat van toepassing is

- ☐ Gesondheidstoestand of gestremdheid
- ☐ Besig met opvoedings- en werksopleiding
- ☐ Persoonlike 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 toepassig	*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.

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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.**	○	○	○	○	○

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104.	**...hoe duidelik die gesondheidssorgvoorsieners 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 .....

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

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?**	○	○	○	○	○

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109.	**Hoe seker is u dat u in staat is om onverwagte gebeurlikhede effektief te kan hanteer?**	○	○	○	○	○
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?**	○	○	○	○	○

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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: ✎.....

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?**	○	○	○	○	○

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		Baie ontevrede	*Ontevrede*	*Nie tevrede of ontevrede nie*	*Tevrede*	*Baie tevrede*
119.	**In hoe 'n mate is u tevrede met u gesondheid?**	○	○	○	○	○
120.	**In hoe 'n mate is u tevrede met u vermoë om u daaglikse aktiwiteite uit te voer?**	○	○	○	○	○
121.	**In hoe 'n mate is u tevrede met uself?**	○	○	○	○	○
122.	**In hoe 'n mate is u tevrede met u persoonlike verhoudings?**	○	○	○	○	○
123.	**In watter mate is u tevrede met u lewensomstandighede?**	○	○	○	○	○

124. Hoe sal u u algemene gesondheid beskryf?

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

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

- ○ Baie beter
- ○ `n bietjie beter
- ○ Feitlik dieselfde
- ○ Ietwat verswak
- ○ Baie verswak

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

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Appendix C: International Spinal Cord Injury Survey - isiXhosa

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

ISPRM International Society of Physical and Rehabilitation Medicine

World Health Organization

ISCOS The International Spinal Cord Society

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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: ######

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

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

Thank you again for your commitment!

Your InSCI-Team

Dr Conran Joseph

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linkcukacha zoMntu

1. **Nceda uchaze isini sakho:**
   - ○ Indoda
   - ○ Ibhinqa

2. **Ingaba wawuzelwe ngoluphi usuku, inyanga nonyaka?**
   USUKU/ INYANGA/ UNYAKA
   □□/□□/□□□□

3. **Ingaba wawuzalelwe kweliphi ilizwe?**
   ✎……

4. **Ingaba utshatile?**
   - ○ Anditshatanga
   - ○ Nditshatile
   - ○ Siyahlalisana okanye liqabane
   - ○ Wahlukene okanye uqhawule umtshato
   - ○ Uhlolokazi

5. **Ngubani ohlala nawe ekhaya?**
   Krwela zonke ezingenayo
   - ☐ Ndihlala ndodwa
   - ☐ Nabantwana abangaphantsi kweminyaka eli-14 ubudala, inani labo: ✎……
   - ☐ Ulutsha oluphakathi kweminyaka eli-14 neli-18 ubudala, inani lalo: ✎……
   - ☐ Abantu abaphakathi kweminyaka eli-18 nama-64 ubudala, inani labo: ✎……
   - ☐ Abantu abangaphezulu kwama-64 ubudala, inani labo: ✎……
   - ☐ Ndihlala kwindawo ekhethekileyo *umz. ikhaya labantu abadala, ikhaya lonyango ngoomongikazi*

6. **Ingaba uyalufumana uncedo ngezinto zakho ozenzayo zemihla ngemihla ekhaya okanye ngaphandle?**
   - ○ Hayi
   - ○ Ewe, ngaba bantu balandelayo:
     Krwela zonke ezingenayo
     - ☐ Usapho
     - ☐ Abahlobo
     - ☐ Abaqeqeshiweyo okanye abancedisi abahlawulwayo

7. **Lithini ibakala eliphezulu lemfundo oligqibileyo? [*iintlobo ezikhethekileyo ngokwelizwe*]**
   - ○ Eliphantsi
   - ○ Elisezantsi
   - ○ Eliphezulu
   - ○ Elingaphaya kweSekondari
   - ○ Efutshane yamaziko aphezulu
   - ○ Isidanga okanye okulinganayo
   - ○ Imastazi okanye okulinganayo

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- 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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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 ziqgithileyo. Ukuba uthe wazifumana ezi ngxaki zempilo, nceda uphawule ukuba ingaba uthe wafumana unyanga okanye hayi (umzekelo ukusela amayeza okanye ukufumana unyango loogqirha okanye abanye abaqeqeshelwe ezempilo).

	1 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

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31.	**Izilonda ngenxa yokuhlala ndawonye, amatyhungutyhungu** *Ezi zilonda zivela njengerhashalala yesikhumba okanye ububomvu kwaye isenokuqhubekeka ibesisilonda esinobumdaka esingapholiyo.*	○	○	○	○	○	○ Ewe ○ Hayi
32.	**lingxako zokuphefumla** *Iimpawu neengxaki zokwasuleleka ziquka iingxaki zokuphefufumla nokunyuka kwemikhunya.*	○	○	○	○	○	○ Ewe ○ Hayi
33.	**Umonzakalo obangelwe kukulahleka kwemvakalelo** *Umzekelo, izilonda zokutsha ezinololwelo olushushu okanye ukuhlala phantsi ixesha elide kufutshane nehitha okanye umlilo.*	○	○	○	○	○	○ Ewe ○ Hayi
34.	**lingxaki zokuhamba kwegazi** *Oku kuquka ukudumba kwemithambo, iinyawo, imilenze okanye izandla, okanye uukwenzeka kwamahlwili egazini.*	○	○	○	○	○	○ Ewe ○ Hayi
		1 Akukho ngxaki	*2*	*3*	*4*	*5 Ingxaki inkulu kakhulu*	*Ukhe/ wakhe wafumana unyango lwayo*
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

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

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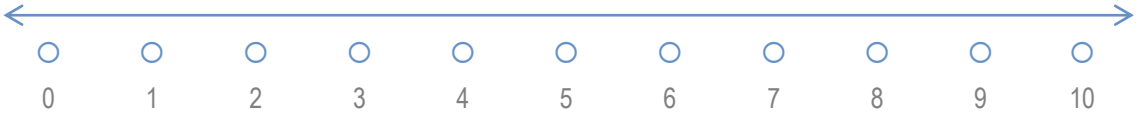
Akukho ntlungu *Iqaqamba kakhulu*



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 zikawonke-wonke?**	○	○	○	○	○
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?**	○	○	○	○	○

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	○ Hayi ○ Ewe → **Ingaba kuyingxaki kangakanani ukuhlala phantsi ixesha elide njengma-30 emizuzu?**	
55.	**Uyakwazi ukuma ungaxhaswanga?** ○ 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*	*Uwukwazi*
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

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62. Ukunxiba impahla kumzimba ongentla

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

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

- ○ 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

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

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

- ○ Ndidinga ukuncediswa kangangoko

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- 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.

G. Ukusetyenziswa kwekhathitha efakwe ngaphakathi

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

H. Ikhathitha yesiqabu

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

***I.* 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

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66. Ukulawula ukuzithuma

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

- Ewe
- Hayi

E. Ukuzithuma kwam…

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

F. Ukuzithuma okungalawulekileyo (“iingozi”) kwenzeka …

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

67. Ukusebenzisa ithoyilethi

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

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- ○ 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 ukuya esitulweni esihambayo

- ○ 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 imigama emifutshane (iimitha ezi-10 ukuya kwi-100)

Ndisebenzisa isitulo esihambayo. Ukuhambahamba, ...

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

Ndihamba imiganyana ephakathi kwaye...

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

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Umsebenzi

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*	*Kwiinxalenye*	*Kancinane*	*Andiyidingi tu kwaphela*	*Andinasidingo sinjalo*
81. Ingaba unazo izixhobo zokukuncedisa ongasisebenzisa xa usemsebenzini ? *umz., izixhobo ezincedisayo zekhompyutha, iitafile ezilungelelaniswayo okanye izixhasi-ngalo /izandleokanye izixhasi-milenze.*	○	○	○	○	○	○

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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.	○	○	○	○

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→ Nceda uye kumbuzo wama-87

84. Ingaba uthanda ukuba nomsebenzi ohlawulwayo?

- ○ Ewe
- ○ Hayi

85. Ingaba uziva ukulungele ukwenza umsebenzi ohlawulayo?

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

86. Zithini izizathu ezibangela ukuba ube awusebenzi ngoku?

Krwela oko kuhambelanayo

- ☐ Imeko zempilo okanye zokukhubazeka
- ☐ Ndisafuunda okanye ndisaqeqeshwa
- ☐ Uxanduva losapho
- ☐ Andiwufumani umsebenzi ondifaneleyo
- ☐ Andiyazi ukuba ndiwufune njani okanye ndiwukhangele njani umsebenzi
- ☐ Andinazidingo zezimali
- ☐ Abazali okanye iqabane alifuni ukuba ndisebenze
- ☐ 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	○	○	○	○

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	Umz., ukungafikeleleki kwezakhiwo zoluntu, iipaki				
88.	**Ukungafikeleli okanye ukungakwazi ukufikelela kumakhaya abahlobo nezalamane**	○	○	○	○
89.	**Iimo zezulu ezingentlanga** *Umz., imozulu, ixesha lonyaka, amaqondo obushushu, ulophu*	○	○	○	○
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, izincedisi-kuhamba 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**	○	○	○	○

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	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

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

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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?**	○	○	○	○	○

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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
- ☐ 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?**	○	○	○	○	○

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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 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?**	○	○	○	○	○

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

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

- ○ Hayi
- ○ Ewe, nceda ucacise: ✎.....

Ikhwaliti yobomi nempilo ngokubanzi

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

	Kwezi ntsuku zilishumi elinesine zidlulileyo ...	*Iphantsi kakhulu*	*Iphantsi*	*Ayikho phantsi kodwa ayikho phezulu*	*Iphezulu*	*Iphezulu kakhulu*
118.	**Ingaba ungayithelekelela kowuphi umyinge ikhwaliti yobomi bakho?**	○	○	○	○	○
		Andaneliseki kakhulu	*Andaneliseki*	*Ndaneliseke ndinganeliseki*	*Ndaneliseki*	*Ndaneliseke kakhulu*
119.	**Ingaba waneliseke kangakanani ngempilo yakho?**	○	○	○	○	○
120.	**Ingaba waneliseke kangakanani ngokwenza imisetyenzana yemihla ngemihla?**	○	○	○	○	○
121.	**Ingaba waneliseke kangakanani ngesiqu sakho?**	○	○	○	○	○
122.	**Ingaba waneliseke kangakanani ngobudlelwane bakho nabanye abantu?**	○	○	○	○	○
123.	**Ingaba waneliseke kangakanani ngeemeko zakho zokuphila?**	○	○	○	○	○

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124. Ngokuphangaleleyo, ungathi impilo yakho:

- ○ Ibalasele
- ○ Ilunge kakhulu
- ○ Ilungile

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- 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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Appendix D: Information sheet - English

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa

Tel: +27 21-959 2542 Fax: 27 21-959 1217

E-mail: vania.erasmus@gmail.com

INFORMATION SHEET

Project Title: Activity limitations and participation restrictions four years after traumatic spinal cord injury in South Africa

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What is this study about?

This is a research project being conducted by Vania van Wyk at the University of the Western Cape. The study investiges activity limitations and participation restrictions of patients after traumatic spinal cord injury. The main motive is to determine what your limitations are within the community after injury 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 – a place convenient for you – with one of the researchers and answer questions related to your injury, functional capabilities, and wellness. This will be done only on one occasion. Each session will last approximately 30-45 minutes.

Would my participation in this study be kept confidential?

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We will do our best to keep your personal information confidential. To help protect your confidentiality all information gathered will be stored safely. 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.

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

What are the risks of this research?

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

What are the benefits of this research?

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 TSCI in South Africa.

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

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

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

There are no direct risks associated with participating in the study. However, if the participant becomes emotional due to the nature of the questions, we will suggest seeking help from an appropriate health professional in the community.

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What if I have questions?

The research is being conducted by Vania Van Wyk at the University of the Western Cape. If you have any questions about the research, please contact me at: 0824869448, e-mail vania.erasmus@gmail.com

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Dr Conran Joseph (Supervisor) at the University of the Western Cape.

Work number 021-959 3662

Cell 0723719276

e-mail: cjoseph@uwc.ac.za

Head of Department: Dr Nondwe Mlenzana; nmlenzana@uwc.ac.za

University of the Western Cape

Private Bag X17

Bellville 7535

UNIVERSITY of the
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Dean of the Faculty of Community and Health Sciences: Prof R Swart;

chs-deansoffice@uwc.ac.za

University of the Western Cape

Private Bag X17

Bellville 7535

The Biomedical Research Ethics Committee (BMREC)

Robert Sobukwe Road

Bellville

Cape Town

7535

Tel: +27219592988

research-ethics@uwc.ac.za

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

Appendix E: Information sheet - Afrikaans

Univeriteit VAN DIE WES Kaap

Privaat Sak: X 17, Bellville 7535, Suid Afrika

Tel: +27 21-959 2542 Faks: 27 21-959 1217

E-pos: vania.erasmus@gmail.com

INLIGTINGSBLAD

Projek Titel: Aktiwiteit beperkings en deelname beperkings vier jaar ná traumatiese spinaalkoord beserings in Suid-Afrika.

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Wat behels hierdie studie?

Dit is 'n navorsingsprojek gedoen deur Vania van Wyk by die Universiteit van die Wes-Kaap. Hierdie studie ondersoek aktiwiteit beperkings en deelname beperkings van pasiënte na traumatiese spinaalkoord beserings. Die belangrikste motief is om te bepaal wat jou beperkinge is binne die gemeenskap ná beserings en voor te stel hoe die gesondheid stelsel verbeter kan word.

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

Jy sal gevra word om 'n sessie by te woon – 'n plek gerieflik vir jou – met een van die navorsers en vrae te beantwoord in verband met jou besering, funksionele vermoëns en welstand. Dit sal gedoen word slegs op een geleentheid. Elke sessie duur ongeveer 30-45 minute.

Sal my deelname in hierdie studie vertroulik gehou word?

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Ons sal ons bes doen om jou persoonlike inligting vertroulik te hou. Om te help jou vertroulikheid te beskerm sal alle inligting wat ingesamel veilig bewaar word. Geen ongemagtigde partye sal toegang tot u inligting het nie. In die geval van 'n verslag of artikel te skryf, sal jou identiteit tot die grootste mate moontlik beskerm word.

In ooreenstemming met wetlike vereistes en/of professionele standaarde, sal ons die toepaslike individue en/of owerhede inligting wat na ons aandag openbaar word, rakende kindermishandeling of verwaarlosing of potensiële skade aan jou of ander.

Wat is die risiko's van hierdie navorsing?

Daar is geen bekende risiko's verbonde aan deelname aan hierdie navorsingsprojek.

Wat is die voordele van hierdie navorsing?

Op 'n persoonlike vlak, sal jy 'n begrip van hoe die beseringjou raak en hoe jy funksioneer met betrekking tot ander met soortgelyke beserings. Vanuit 'n breë perspektief, hierdie inligting kan help met die versterking van gesondheid stelsels vir persone met traumatiese spinaalkoord beserings in Suid-Afrika.

Moet ek in hierdie navorsing deelneem en kan ek ophou deelneem op enige tydstip?

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Jou deelname in hierdie navorsing is heeltemal vrywillig. Jy kan kies om nie deel te neem of nie. As jy besluit om deel te neem in hierdie navorsing, kan jy ophou deelneem op enige tyd. Indien jy besluit om nie deel te neem aan hierdie studie, as jy ophou deelneem op enige tyd, sal jy nie benadeel word of enige voordele verloor wat jy andersins voor kwalifiseer nie.

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

There are no direct risks associated with participating in the study. However, if the participant becomes emotional due to the nature of the questions, we will suggest seeking help from an appropriate health professional in the community.

Daar is geen direkte risiko's verbonde aan deelname aan die studie nie. Egter, indien die deelnemer emosioneel raak as gevolg van die aard van die vrae, sal ons voorstel dat u hulp van 'n toepaslike gesondheid professionele in die gemeenskap kry.

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Wat gebeur as ek vrae het?

Die navorsing is gedoen deur Vania Van Wyk by die Universiteit van die Wes-Kaap. As jy enige vrae het oor die navorsing, kontak my asseblief by: 0824869448, e-pos vania.erasmus@gmail.com

Indien jy nog enige vrae met betrekking tot hierdie studie en jou regte as 'n navorsing 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.

Werk nommer: 021-959 3662

Sel: 0723719276

e-pos: cjoseph@uwc.ac.za

Hoof van Departement: Dr Nondwe Mlenzana: nmlenzana@uwc.ac.za

Universiteit van die Wes-Kaap Private Bag X17

Bellville 7535

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Dekaan van die Fakulteit van gemeenskap en Gesondheidswetenskappe: Prof R Swart;

chs-deansoffice@uwc.ac.za

Universiteit van die Wes-Kaap Private Bag X17

Bellville 7535

The Biomedical Research Ethics Committee (BMREC)

Robert Sobukwe Straat

Bellville

Kaapstad

7535

Tel: +27219592988

research-ethics@uwc.ac.za

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

Appendix F: Information sheet - isiXhosa

IDyunivesiti YASE Ntshona Koloni

Ibhokisi ebucala X 17, Bellville 7535, Mzantsi Afrika

Nombola: +27 21-959 2542, Fekisi: 27 21-959 1217

E-mail: vania.erasmus@gmail.com

Sheet Ulwazi

Isihloko soPhando lweProjekthi: Izinto ezivalela intsebenziswano nokuqhubeka emva kweminyaka emine ulimine umnqongo eMzantsi Africa.

Lungantoni oluphando phezulu?

Oluphando nzulu iwenziwe ngu Vania van Wyk kwi Nyuvesi yasentshona koloni le yintlangi nisela yezinto ezisetyenziswayo koluphando iwezinto ezivalela nezithintelayo izizul, ezilimele umngongo. Injongo kukwahlula ukuba zintoni ongakwezi ukuzifikelela kumphakathi emveni kokulimala and nokuzama ukukwazi uba impilo yekwo ingaphculwe kanjani.

Izokuthini imibuzo ndakuba ndivumile ukuba yinxalenye?

Izakucelwa ungene imihlengano- kwindawo elungele wena, kunye nomphandi lowo ukuphendela imibuzo mayela nokulimala kwakho, inezinto okwezi ukuzenza kunye nemfilo yekho emva kokulimala. Lento izokwenziwa nje kube Kanye ngeloxasha kuzakuthatha imizuzu engama 30-45 imizuzu.

Ingaba inxaxhebe yam koluphando izakugcinwa iyimjihlelo na?

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Zizakukwenza konke okusemendleni ukugcinca inkcukacha zakho zibe yimfihlo. Ukunceda ukhuseleko, zonke inkcukacha ezigokeleewayo zizakuekwa kwindawo ekhuselekileyolefihlakeleyo. 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 uba ndibe koluphando okanye ndingayyeka nangaliphi ixesha ndifuna?

Inxhaxheba yakho koluphanda ayisosinyanzelo, uyenza ngokuzitha ndela or ngokuzikwethela. Ungazikhethela ukungathayhi nxhexheba konke konke. Ukuba ugqibe ukungaqhubeki noluphando, okanye uyeke nangaliphi ixeshe, awuzokohlwaywa okanye uphulukane nayo nantoni na.

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Ndingabakho koluphando ndingakwazi ukuyeka ukuthatha inxaxheba naangaliphi ixesha?

Inxaxheba yakho koluphando igqibelele kkubuvolontiya ungakheta ungaluthathi konke konke. Ukuba ukucinga ngokungathathi nxaxheba kwezi zikufundo okanye ukuba uyayeka ukuthatha inxaxheba nangaliphina ixesha, awuzukupena layizwa okanye uphulikana nezinto okhwalipaya kuzo.

Lungakhona uncedo endinolufumana ukuba ndingachaphszeleko ngokuthatha inxaxheba kwezizifundu?

Akukhobungozi bungqamene nokuthatha inxaxheba kwezi zifundo nakanjani, ukuba umthathi nxaxheba uva buhlungu xa kubu-zwa imbuzo, sizakuthatha isigqibo sokubona singanceba sifumane ingaohgqonya kwezempolo ekuhlaleni.

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Ukuba ndinemibuzo?

Oluphando luqhutywa nguVania van Wyk kwi Dyunivesity yase Ntshona koloni. Ukuba unayo imibuzo malunga noluphando, nceda nditsalele kwezi: 0824869448, nayili vania.erasmus@gmail.com

Ukuba unanye nje eminye imibuzo malunga nezizifundo ilungelo lakho nje ngomphandi othatha inxaxheba okanye ufuna okuchza ezinye iingxaki othe wahlangana nazo ezisondele kwezi zifundo nceda qhangamshelana: Dr Conran Joseph kwi Dyunivesity yase Ntshona

Linombolo zomsebenzi: 021-959 3662

cell: 0723719276

i-mayili: cjoseph@uwc.ac.za

Intloko Yecandelo: Dr Nondwe Mlenzana; nmlenzana@uwc.ac.za

kwi Dyunivesity yase Ntshona koloni Ibhokisi ebucala X17

Bellville 7535

Dean of the facualty of health science: Prof R Swart; chs-deansoffice@uwc.ac.za

kwi Dyunivesity yase Ntshona koloni Ibhokisi ebucala X17

Bellville 7535

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WESTERN CAPE

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Appendix G: Consent form - English

CONSENT FORM

Title of Research Project: Activity limitations and participation restrictions four years after traumatic spinal cord injury in South Africa

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.

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Participant's name……..

Participant's signature…….

Date……

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Appendix H: Consent form- Afrikaans

Toestemming vorm

Titel van Navorsingsprojek:Aktiwiteit beperkings en deelname beperkings vier jaar ná traumatiese spinaalkoord beserings in Suid-Afrika.

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

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Deelnemer se naam.....

Deelnemer se handtekening.....

Datum.....

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Appendix I: Consent form - Isixhosa

Ifomu Yomsebenzi

Isihloko soPhando lweProjekthi: Izinto ezivalela intsebenziswano nokuqhubeka emva kweminyaka emine ulimine umnqongo eMzantsi Africa.

Uphando luye lwachazwa kum ngolwimi endiluqondayo. Imibuzo yam malunga nokufunda iphendulwe. Ndiyayiqonda into endiyithatha inxaxheba yam lyakubandakanyeka kwaye ndiyavuma ukuthatha inxaxheba kwindlela endizikhetheleyo nekhululekileyo. Ndiyaqonda ukuba ubumna abusoze baziswa nakubani na. Ndiyaqonda ukuba ndinako ukurhoxisa izifundo nanini na ngaphandle kokunika isizathu kwaye ngaphandle kokoyika nemiphumela emibi okanye ukulahleka kwezibonelelo.

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Igama lomthathinxaxheba ……..

Isinyatheliso somthathi nxaxheba …….

Umhla: **……**

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Appendix J: Ethics clearance

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OFFICE OF THE DIRECTOR: RESEARCH
RESEARCH AND INNOVATION DIVISION

Private Bag X17, Bellville 7535
South Africa
T: +27 21 959 4111/2948
F: +27 21 959 3170
E: research-ethics@uwc.ac.za
www.uwc.ac.za

9 February 2018

Ms V van Wyk
Physiotherapy
Faculty of Community and Health Sciences

Ethics Reference Number: BM17/10/10

Project Title: Activity limitations and participation restrictions four years after traumatic spinal cord injury in South Africa.

Approval Period: 8 February 2018 – 8 February 2019

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

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

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

The permission from the facility and health departments must be submitted for record-keeping.

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

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

PROVISIONAL REC NUMBER -130416-050

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