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Experience of Bowel, Bladder and Sexual Problems and the effectiveness of a health program on Quality of Life and mental health in people with spinal cord injury in Manguzi.

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Master of Science in Physiotherapy.

DECLARATION

I, Lauren Meagan Tomes, declare that the research reported in this dissertation is my own, original research except where specifically indicated and acknowledged. This dissertation will be submitted in fulfilment of the degree, Master of Science in Physiotherapy. This dissertation has not been submitted for any degree or examination at any other university.

Candidates Name

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Date: 10/09/2023

SUPERVISOR DECLARATION

I, Sonti Pilusa hereby confirm that I have read the content of this dissertation and approved of its submission.

Supervisor:

Dr. Sonti Pilusa

Signature:

Date: 10/09/2023

ABSTRACT

Background: The quality of life of people with spinal cord injury is significantly affected by secondary health conditions such as bowel, bladder, and sexual problems. Literature on the experiences of bowel, bladder, and sexual problems is limited and studies on health interventions in people with SCI are also scarce in South Africa.

Aim: To explore the experience of bowel, bladder and sexual problems and the effectiveness of a health program on the quality of life and mental health, as well as to determine the effectiveness of a health program on the quality of life (QoL) and mental health of people with SCI in Manguzi, KwaZulu Natal.

Method: This study was a mixed study. An explorative qualitative study design using semi-structured interviews was employed. The interviews were transcribed verbatim, and content analysis was conducted to identify the themes and categories. A Quasi-Experimental quantitative design was used. A face-to-face health program on the prevention and management of bowel, bladder, and sexual problems in SCI was conducted for the participants with SCI. WHOQoL-Bref and SF-12 questionnaires were administered before and six weeks post-intervention respectively. Paired t-test was used to identify changes in QOL and mental health pre and post-intervention. Significance was set at p-value ≤ 0.05.

Results: The themes that emerged from the experience of bladder and bowel problems were "no control" and "frustration". The categories related to the experiences were: types of bladder and bowel problems, managing bladder and bowel problems and the effects on well-being**:** The main theme for the experience of sexual health problems was "Dissatisfaction". The categories were: types of sexual health problems, factors influencing sexual activity, the impact of sexual problems, and the management of sexual health problems. The long-term care needs for bowel and bladder problems included access to proper toilets, nappies, medication (Dulcolax), ease of bowel movement, and health information on diet and how to manage their bowel and bladder problems better. The long-term care needs for sexual health problems included the need for medication (sexual enhancement pills) and information on how to manage sexual health problems. There were no statistically significant changes in the pre-test and post-test scores of both the quality of life and mental health.

Conclusion: The findings show that bowel, bladder, and sexual problems affect people with spinal cord injury. There is a need to ensure people with SCI are empowered with information, skills, and resources to manage these secondary complications. The findings also show that a health program focusing only on health education alone will not affect mental health and quality of life in people with SCI. Other factors influencing the quality of life and mental health of the people with SCI such as the presence of secondary health conditions, social support, access to health care services and unemployment should also be considered when developing future interventions.

Keywords: spinal cord injury, bowel and bladder problems, sexual problems, long-term care needs, secondary health conditions, mental health, quality of life

DEDICATION

This study is dedicated to God for the grace and strength to complete this study. I dedicate this study to my family and friends who have shown me unwavering love and support. I also dedicate this study to my supervisor Dr Sonti Pilusa for all her support, friendship, prayers, guidance and most importantly her patience. May the Lord bless you all profusely. Lastly, I dedicate this study to all the people living with spinal cord injury, not just in Manguzi KwaZulu Natal, but rural South Africa at large. May this study be the heed to the call that allows us, as healthcare professionals to meet your needs holistically.

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"Though the storms may come, and the winds may blow, I'll remain steadfast.

And let my heart learn, when You speak a word, it will come to pass.

Great is Your faithfulness to me,

From the rising sun to the setting same, I will praise Your name…"

How this song has carried me through my Master's journey that I've called "character building". Thank you, Lord - indeed Your promise still stands. God is intentional, there are no mistakes on our journey, and I am so grateful to be at the finish line. It was not easy, but by God's sufficient grace I have conquered.

Words cannot express my gratitude to my supervisor, Dr Sonti Pilusa for her beautiful heart, invaluable patience, and feedback. More so, thank you for your prayers and guidance, they kept me going. I will never forget our very eventful "Bundu Bashing" week in rural KwaZulu Natal – I could not have asked for a better supervisor to hold my hand on this journey. You truly are remarkable.

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Lastly, I would be remiss in not mentioning my family and friends, especially my parents and siblings. Their belief in me has kept my spirits and motivation high especially when I felt like I had no fight left in me. Thank you for your unconditional love and support throughout this journey.

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From the bottom of my heart, thank you and God bless you all xx

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LIST OF ACRONYMS AND ABBREVIATIONS

NPO – Non-Profit Organization

SHCs – Secondary Health Conditions

SCI – Spinal Cord Injury

SF12 – Short Form 12 Questionnaire

QoL – Quality of Life

UTIs – Urinary Tract Infections

WHO – World Health Organization

WHOQoL-Bref – World Health Organization Quality of Life – Bref Questionnaire

DEFINITION OF TERMS AND CONCEPTS

Spinal cord injury – The term 'spinal cord injury' refers to damage to the spinal cord resulting from trauma (e.g. a car crash) or from disease or degeneration (e.g. cancer) (WHO, 2013).

Secondary health conditions (SHCs): secondary health conditions also referred to as secondary complications or secondary conditions. Secondary health conditions are health conditions that develop in people living with disabilities and examples include bowel, bladder, sexual problems, contracture, and pain (Rimmer et al., 2011).

Prevalence - the rate, or the proportion of persons in a population who have a particular disease or attribute at a specified point in time or over a specified period of time (NIMH, 2022).

Mental health - Mental health is a "state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community" (WHO, 2020).

Quality of life - Quality of Life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHO, 2012).

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CHAPTER 1

1.0 Background

1.1 Introduction

Spinal cord injury (SCI) is a life changing event that can affect both "personal life and relationships" (Ide-Okochi et al., 2013). The prevalence of SCI has an estimated prevalence of over 2.5 million worldwide (Emmanual, 2019). In South Africa, according to the QuadPara Association the estimated prevalence of SCI in 2009 was approximately 50 000 people (Joseph et al., 2017).

Spinal cord injury brings a lot of changes in an individual's life. An injured person is required to adjust and rethink how to do simple, everyday tasks such as eating, toileting and general activities of daily life. Moreover, people with SCI experience many secondary health conditions (SHCs) also referred to as secondary complications (SCs). In this study, the term that will be used is secondary health conditions. These secondary health conditions are complications that people living with disabilities can experience (Rimmer Chen & Hsieh, 2011). Some of the SHCs that may occur after SCI include pain, pressure sores, spasms, postural hypotension, pneumonia, neurogenic bowel and bladder problem, mental health problems and sexual problems (Brinkhof et al., 2016; Jensen al., 2013). Secondary health conditions affect overall health (Pilusa et al., 2021) often leading to re-hospitalisation and sadly, death (Mashola et al., 2019; Madasa et al., 2020). Since SCI is a long-term disability that requires long term care, there is a growing need to strengthen the prevention of these SHCs (Pilusa et al., 2021; Guilcher et al., 2013).

Symptoms of pain, bowel and bladder problems are common SHCs. The estimated prevalence of bladder problems is approximately 81% (Ginsberg, 2013). Bladder problems are reported to be highly problematic SHCs due to the notable effects on the wellbeing of people living with SCI (Taweel & Seyam, 2015). Types of bladder problems can be classified according to involvement of the detrusor and sphincter activity (Hagen et al., 2014). This can either lead to incontinence or residual urine. Incontinence, renal impairment, urinary tract infection (UTI) also increases the risk for further SHCs (Hagen et al., 2014). People living with SCI are prone to recurring UTIs which often results in more than 20% hospitalisation and if left untreated can lead to renal failure which is often the main cause of death in people with SCI (Alsulihem & Corcos, 2019; Taweel et

al., 2015). Other related complications include kidney and bladder stones and poor quality of life (Taweel et al., 2015). Bladder problems in individuals with SCI affects overall well-being and negatively affects participation in social life (Fuseini et al., 2019).

Bowel problems are also closely related to bladder problems because SCI can disrupt communication between the brain and the nerves in the spinal cord that control both bowel and bladder function (Emmanual, 2019). The estimated prevalence of bowel problems occurs in almost half of people living with SCI (46.9%) Sezer et al., (2015). The types of bowel problems depend on the level and severity of the lesion. The different types of bowel problems include: "constipation, faecal incontinence, impaction, megacolon, hemorrhoids, rectal bleeding, prolapse, and formation of anal fissures in some cases abdominal pain" according to, Emmanual, (2019) and Lynch et al., (2001). Bowel problems are not fully understood as symptoms differ depending on the type and level of SCI (Hughes, 2014). According to Krassioukov et al., (2010) there are two presentations of bowel dysfunction SCI, namely upper motor neuron (UMN) bowel syndrome which indicates that injury has occurred above the conus medullaris and lower motor neuron (LMN) bowel syndrome which indicates that the injury has occurred at the conus medullaris and the cauda equina. Upper motor neuron (UMN) bowel syndrome is commonly characterised by constipation and fecal retention, whereas LMN is characterised by fecal incontinence (Krassioukov et al., 2010). Some challenges associated with bowel problems can also be attributed to the amount of time required for bowel care and the negative impact it has on quality of life and participation in social life (van der Meer et al., 2017; Mashola et al., 2020)

Sexual problems are also closely linked to bowel and bladder problems as the nerves responsible for sexual, bowel and bladder function are all located in the same region of the spinal cord at the thoracolumbar junction (Park et al., 2017). The prevalence of sexual problems experienced in a study conducted by Park et al., (2017) among people with SCI is 60.8%. Sexual problems such as decreased libido, erectile problems, ejaculatory problems, pain and decreased lubrication affects various aspects of one's life including physical, mental, and social aspects (Aikman et al., 2018; Giannopapas et al., 2021). Immediately after a SCI, most patients focus on their physical function. However, when they eventually accept their injury, dealing with sexuality is also an important step in the rehabilitation process (Hagen, 2015). The effect of SCI on sexual dysfunction is often worsened by neurological disorders, bladder and bowel management,

spasticity, pain, and low self-esteem. If it is a lesion-related problem it can also influence sexual activity, satisfaction, and sexual response (Lombardi et al., 2010).

The changes caused by SCI can be extremely overwhelming and can affect mental health. A study, conducted by Michigan University (2020) found that adults with SCI are at higher risk of developing mental health disorders, including depression and anxiety when compared to adults without SCI. There is evidence showing that people with SCI stress and worry about their health and the effects of SHCs in their lives (Pilusa et al., 2021; Fuseini., et al. 2019). A study looking at the experiences of people with SCI revealed that the presence of bladder and bowel incontinence causes a lot of fear for leakage thus limiting participation in social events (Pilusa et al., 2021; Fuseini., et al. 2019). Similarly, a study by Mashola et al., (2019) found a significant association between depression and urinary incontinence among people with SCI. There is a need to strengthen care for people with SCI specifically for SHCs prevention and management.

The management of an individual with SCI is complex and lifelong, requiring a multidisciplinary approach. A functional, goal-oriented rehabilitation program including health education should enable the individual with a SCI to live as independently as possible. The current practice during the rehabilitation phase mainly focuses on activities of daily living neglecting long-term care needs for bowel, bladder, and sexual problems (Pilusa et al., 2021). Also, evidence shows that prevention and management of SHCs are not adequately addressed and tends to be reactive rather than proactive (Guilcher et al., 2013). As such leaving people with SCI not knowing how to prevent and manage SHCs increases poor health outcomes.

Access to healthcare is integral to overall health for all people with disability (Hashemi, 2020). The South African health care system however, does not prioritise rehabilitation care for people with SCI. According to Maart & Jelsma (2013) people with chronic conditions such as SCI are in most need of additional healthcare yet are least able to access it. These people are also believed to experience widespread poor access to healthcare services, largely due to inaccessible environments and discriminatory belief systems and attitudes (Maart et al., 2013). As such there is a need to understand the health challenges experienced by people with SCI and their unmet needs.

1.2 Problem Statement

People with SCI experience SHCs such as bladder and bowel and sexual health problems which need long-term care and support to prevent and manage them. The current practice during the rehabilitation phase mainly focuses on activities of daily living neglecting long-term care needs for bowel, bladder, and sexual problems. Evidence also shows that prevention and management of SHCs are not adequately addressed. According to a study by Guilcher et al., (2013) people with SCI expressed that their needs were unmet, they identified their need for information and education on topics such as sexual and reproductive health as well as the need for psychosocial care. This study also highlighted barriers to accessibility and availability of services. As such leaving people with SCI do not know how to manage their SHCs and where to seek for health. In South Africa there is limited literature on the experience of people with SCI on bladder and bowel and sexual health problems and their management as well as how it affects both their mental health and QoL. This highlights the need to understand the long-term care needs related to sexual problems, bowel and bladder sof people with SCI as there are gaps in the long-term management of the SHCs. There is a need to understand current experiences, challenges experienced and unmet needs.

1.3 Study Aim

To explore the experience of bowel, bladder and sexual problems and the effectiveness of a health program on the quality of life and mental health in people with SCI in Manguzi.

1.4 Research Objectives

1. To explore the lived experience of bowel, bladder, sexual problems in people with SCI.
2. Identify long-term care needs related to bowel, bladder, and sexual problems in people with SCI.
3. To determine the effectiveness of the health program for bowel, bladder, and sexual problems on quality of life (QoL).

4. To determine the effectiveness of the health program for bowel, bladder, and sexual problems on mental health in people with SCI.

1.5 Significance

The findings of this study will give us a better understanding of the SHCs experienced by people with SCI. Secondly, the findings of this study will inform care provided to people with SCI related to bowel, bladder as well as sexual health problems. This study findings can influence clinical practice for SCI rehabilitation to provide the needed care and support. In addition, the findings of the study can inform health interventions to address these SHCs. It will also influence future research with regards to self-management of SHCs in people living with SCI and help develop evidence-based practice guidelines for clinicians and care providers. More so, long-term this study could influence the management of long-term SHCs in people with SCI as well as improve overall QoL of people living with SCI (Parittotokkaporn et al., 2020).

1.6 Dissertation Outline

Chapter 1 –An overview of the study background, problem statement, study aim, objectives and the significance of this study was presented.

Chapter 2 –Relevant literature focusing on secondary health conditions such as pain, bowel, bladder, and sexual problems will be reviewed. The chapter will also include a review on the management of these problems and looks at the effects on mental health and quality of life.

Chapter 3 – Will outline the methodology used to conduct this research. The research design, the study setting, the study participants, methods used to collect data, and data collection procedures were outlined, all ethical protocols as per HREC and NREC were considered.

Chapter 4 – Research paper 1 which is titled "Sexual health problems in people with spinal cord injury in Manguzi, KwaZulu Natal: Experience and long-term care needs."

Chapter 5 – Research paper 2 which is titled "Bowel and bladder problems in people with spinal cord injury in Manguzi, KwaZulu Natal: Experience and long-term needs."

Chapter 6 – Research paper 3 which is titled "Health intervention for people with spinal cord injury addressing bowel, bladder, and sexual problems, KwaZulu Natal, South Africa."

Chapter 7 – Discusses the findings from chapters 4 – 6 in accordance with the study aims and objectives.

Chapter 8 –Summarizes the study findings, state the study limitations and the recommendations.

CHAPTER 2 – Literature Review

2.0 Introduction

This chapter will review the literature on bowel, bladder, and sexual problems in people with spinal cord injury (SCI) and health programs on quality of life and mental health in people with SCI. This chapter is divided into four sections which are sub-divided as follows: Section one looks at the anatomy and physiological deficits of SCI. Section two looks at the causes and prevalence of SCI. Section three looks at secondary health conditions (SHCs) in SCI and their impact on mental health and quality of life and section four, the health intervention strategies for people with SCI.

Various online databases including PubMed, the Pedro database, Cochrane reviews, and Google Scholar were used. Keywords used included 'spinal cord injury', 'incidence', 'prevalence', 'mental health', 'quality of life', 'bowel problems', 'bladder problems', 'sexual problems', 'health education' and 'management''. The articles were all screened by individual titles as well as the relevance and were not older than ten years. Through this process, suitable articles were selected for review. An individual review of journals and textbooks was also conducted and in addition to this, websites such as Google, the World Health Organization, the International Spinal Cord Injury Society, the South African Medical Journal, and the South African Journal of Physiotherapy were accessed for further beneficial information.

2.1 Spinal cord injury: Anatomy and physiological deficits

The spinal cord is one of the most complex yet fascinating parts of the nervous system. Within the spinal column lies the spinal cord, a vital aspect of the central nervous system (CNS). The three primary roles of the spinal cord are to send motor commands from the brain to the body, send sensory information from the body to the brain, and coordinate reflexes (Harrow-Mortelliti et al., 2022). The spinal cord is organised segmentally, with thirty-one pairs of spinal nerves emerging from it (Khan, 2022). These spinal nerves are mixed nerves having a motor component that helps control all the muscles and a sensory component that helps in receiving the sensory

information from these areas (Khan, 2022). The nerves responsible for sexual, bowel and bladder function are all located in the same region of the spinal cord at the thoracolumbar junction and they are namely lumbar sympathetic, sacral parasympathetic and sacral somatic nerves (Park et al., 2017). The thoracolumbar junction is an area where the end of the spinal cord changes to the conus medullaris and then to the cauda equina, hence an injury to this area may increase vulnerability of bladder, bowel and sexual dysfunction (Park et al., 2017).

General damage to the spinal cord, therefore, disrupts the channel between the body and brain, and can lead to deficits in sensation, movement, and autonomic regulation, as well as death (Harrow-Mortelliti et al., 2022). In the majority of cases, people with spinal cord injury (SCI) present with an upper motor neuron (UMN) lesion, which is clinically confirmed by a positive clonus sign, hyperreflexia, an increase in muscle tone, and general motor weakness (Emos at al., 2020). Beyond the loss of movement control, typical deficits include the loss of bladder and bowel control, declined sexual functions and chronic pain, among others (Ahuja et al., 2017; El-Masri et al., 2012). Spinal cord injury (SCI) can occur at any age, and the damage is irreversible. However, constant improvements in healthcare and treatment, as well as increased awareness about the needs of patients over the last century, have significantly improved the quality of life (QoL) and lifespan following SCI (Venkatesh, 2019).

2.2 Causes of SCI

Any mechanism that causes injury to the vertebral column or the bones in the vertebral spine can damage the spinal cord. The causes of SCI include falls, acts of violence, sports and recreation injuries, diseases, and motor vehicle accidents (WHO, 2013). Globally the main cause for SCI is due to traumatic causes although the proportion of non-traumatic SCI is growing (WHO, 2013). In Africa, the main cause of traumatic SCI is motor vehicle accidents, followed by falls and then acts of violence (Draulans et al., 2011). For non-traumatic SCI, tuberculosis (TB) as the most common cause, followed by malignant reasons (Draulans et al., 2011). Currently, South Africa does not have a national database or surveillance for SCI. According to Joseph et al., (2015), a study conducted in Cape Town, South Africa suggests that assault accounts for 59.3% of cases followed by motor vehicle accidents which account for 26.3% and falls account for 11.7% of cases, however there is limited evidence. There is no direct link between bowel, bladder and

sexual dysfunction to the cause of SCI, however clinical presentation will differ depending on the level and severity of the SCI (Pavese et al., 2023).

2.3 Prevalence of SCI

The prevalence of SCI is increasing globally. For the last 30 years, its global prevalence has increased from 236 to 1298 cases per million people (Anjum et al., 2020). The estimated global rate of SCI falls between 250,000 and 500,000 individuals every year (Khorasanizadeh et al., 2019). The actual prevalence rates of SCI are, however, extremely underreported (Singh et al., 2014; Kang et al., 2018). The lowest prevalence of SCI globally was reported as 440 cases per million in Iran while prevalence rates of 490 and 526 cases per million in Australia and Iceland respectively (GBD 2016 Traumatic Brain Injury and Spinal Cord Injury Collaborators, 2018). A global estimate of SCI prevalence has been reported as 3680 cases per million, an overall estimate of 27 million people living with SCI worldwide (GBD 2016 Traumatic Brain Injury and Spinal Cord Injury Collaborators, 2018). This article also reports that higher prevalence rates are generally observed in regions with a higher socio demographic index (SDI). Western Europe and high-income Asia Pacific were reported to have the highest global SCI prevalence rates at 8540 and 8210 cases per million people respectively. Middle SDI regions were found to have an estimated SCI prevalence rate of 2310 cases per million people (GBD 2016 Traumatic Brain Injury and Spinal Cord Injury Collaborators, 2018).

According to continents, Furlan et al., (2013) report that America has an estimated annual SCI prevalence of 50-1298 cases per million people while in Europe, an estimated 227-526 cases per million people were reported. In Asia and the Middle East, prevalence estimates of 236-849 cases per million people were made while Oceania presented estimates of 681 cases per million people. No actual SCI prevalence data has been outlined for the African continent, however, estimates for Sub-Saharan Africa have been made at 1910 cases per million people while for South Africa an estimate of 2060 cases per million people has been reported according to GBD (2016) Traumatic Brain Injury and Spinal Cord Injury Collaborators, 2018.

In low- and middle-income countries (LMICs), the burden of traumatic spinal cord injury (TSCI) is largely unknown (Stothers et al., 2017). Spinal cord injury is also said to be more common in

Africa than in Europe (Musubire et al., 2017). In Sub-Saharan Africa, SCI is associated with a high morbidity (about 50% persistent disability) and mortality (around 10% in admission) rates and this has huge financial implications for patients and the healthcare systems (Musubire et al., 2017). The reported prevalence of SCI in Sub-Saharan Africa is estimated at a range from 21 – 29 cases per million people and the occurrence of SCI is likely to be fatal within a year (Stothers et al., 2017). In South Africa, there is very limited data on SCI, and this is largely because there is a lack of a national registry, moreover, information registration is less accurate and unreliable, so it becomes harder to assess the global burden of SCI (Joseph et al., 2017 & Golestani et al., 2022). The QuadPara Association of South Africa estimated in 2009 that approximately 50000 people in South Africa are living with an SCI (Joseph et al., 2017). However, a recent study by Joseph et al., (2015), reported a prevalence rate of 75.6 cases per million people in South Africa. The main cause of SCI in South Africa was found to be assault, which accounts for approximately 60% of all cases, followed by motor vehicle reported incidents (26%) and then falls (12%).

The primary injury phase entails the anatomical and physiological changes caused by trauma or diseases in the spinal cord area. The damage to the bones, ligaments will determine the severity of the injury. Depending on the level of the lesion, spinal cord injury can affect the sympathetic nervous system, and hindrance of the parasympathetic nervous system resulting in an increased sympathetic activity below the injury level. This can result in both motor and sensory fallout below the level of the lesion affecting the following systems: cardiovascular, thermoregulatory, pulmonary, urinary, gastrointestinal and not forgetting sexual problems which can all be common as the body is in a state of autonomic dysfunction (Hagen, 2015; Henke et al., 2022). The autonomic nervous system (ANS) is made up of two systems, parasympathetic and sympathetic and they are responsible for maintaining homeostasis in the body (Henke et al., 2022). However, after SCI the supraspinal innervation to the ANS is disrupted and this can cause the sympathetic system to tone down and the parasympathetic system to preside and this causes lack of control of bowel and bladder as well as sexual dysfunction (Henke et al., 2022). Spinal cord injury (SCI) is a devastating neurological state producing physical dependency, morbidity, psychological stress, and financial burden. Rehabilitation during the acute, subacute and

intermediate phases focus on preventing SHCs, promoting, and enhancing neuro recovery, maximising function, and establishing optimal conditions for long-term maintenance of health and function (Burns et al., 2017).

The next section will highlight the impact of SCI on mental health and quality of life.

2.4 Spinal cord injury and their impact on mental health and quality of life

Mental health problems such as depression and anxiety disorders are common secondary health conditions following SCI due to the lives of people with SCI, along with those around them having been changed forever (Budd et al., 2022). Mental health by definition is a positive concept related to the social and emotional well-being of people and communities (United Nations, 2011). The concept relates to the enjoyment of life, ability to cope with stress and sadness, the fulfilment of goals and potential, and a sense of connection to others. People with SCI experience, on average, higher levels of anguish and lower levels of overall life satisfaction compared to the general population (Post & Leeuwen, 2012). The estimated prevalence for depression is 22% and 27% for anxiety (Williams & Murray, 2015; Le & Dorstyn, 2016). The World Health Organization, (2013) estimated 20-30% of people with SCI show clinical signs of depression. Depression negatively affects their function and overall well-being (WHO, 2013). It is therefore important to better understand the factors that are related to mental health and overall QoL in the SCI population to help inform interventions and health policies.

Factors affecting mental health in people with SCI include socioeconomic inequalities, social relationships, financial strain (Zürcher et al., 2019). Other factors include SHCs that come with living with SCI such as pain, bladder, bowel and sexual problems that can all be extremely overwhelming and affect mental health (Callaway et al., 2015). There is evidence showing that people with SCI stress and worry about their health and the effects of SHCs on their lives (Pilusa et al., 2021; Fuseini et al., 2019). Besides SCI and its impact, SHCs can also affect QoL.

Living with a lifelong condition can affect overall QoL. Quality of life is defined as an individual's perception of their own position in life, which is defined by their own culture, values, goals, expectations, and concerns (WHO, 1994). Spinal cord injury (SCI) affects all aspects of life. In most people with SCI, there is a reduced ability to participate in employment,

which can be a considerable financial burden to their families (Draulans et al., 2011). Employment offers people with SCI an opportunity to participate in productive work, achieve social integration and have an improved quality of life (Pefile et al., 2019). Most people with SCI are unemployed hence, the financial and health impact of managing bowel and bladder must not be underestimated. Living with a disability can be financially costly due to disability related costs such as day to day support and access to care for SHCs (Hanass-Hancock et al., 2017). According to Geyh et al., (2010), QoL in people with SCI are congruent with mental health, employment, overall participation, accessibility, relationships, social support, and coping strategies. Secondary health conditions (SHCs) are important predictors of QoL and that it can affect emotional wellbeing, reduce social activity, community participation, relationship satisfaction and health related QoL of people with SCI (Mashola et al., 2019).

This next section will highlight SHCs associated with SCI, bowel, bladder, and sexual problems will be explored in further detail.

2.5 Secondary health conditions and SCI

People with SCI are vulnerable to developing secondary health conditions (SHCs) or at times termed secondary complications (Adriaansen et al., 2013). Secondary health conditions are impairments that can occur by virtue of living with a disability. There is range of SHCs that people with SCI experience such pain, pressure sores, spasms, postural hypotension, pneumonia, neurogenic bowel and bladder problems, mental health problems and sexual problems (Brinkhof et al., 2016; Jensen al., 2013). These SHCs occur throughout the continuum of care, acute phase, rehabilitation and post discharge (Adriaansen at al., 2013; Wahman et al., 2019). In this review the following SHCs will be discussed: bowel, bladder, and sexual problems.

2.5.1 Bladder problems

Bladder problems are one of the common SHCs in people with SCI. They occur as a result of damage to the ANS (Henke et al., 2022). Bladder problems are diagnosed through careful examination and establishing the level of the lesion, the severity of the injury and whether it is

complete or incomplete (Taweel et al., 2015). The estimated prevalence of bladder problems is approximately 44% - 62% (Madasa et al., 2020; StrØm et al., 2022). Bladder problems are reported to be highly problematic SHCs and are prioritised because they can have significant threats to the wellbeing of patients such as incontinence, renal impairment and and urinary tract infections (UTIs) (Taweel et al., 2015). Types of bladder problems can be classified according to involvement of the detrusor and sphincter activity which are established via urodynamic testing (Hagen et al., 2014; Taweel et al., 2015). Bladder problems also increase the risk for further SHCs such as autonomic dysreflexia which causes high blood pressure, bradycardia, sweating and headaches all of which could cause increased risk for haemorrhage on the brain (Hagen et al., 2014; Taweel et al., 2015). People with SCI are prone to repeated UTIs which often results in more than 20% hospitalisation and if left untreated can lead to renal failure which is often the main cause of death in people with SCI (Alsulihem et al., 2019; Taweel et al., 2015). Other related complications include kidney and bladder stones and poor quality of life (Taweel et al., 2015). Bladder problems in individuals with SCI affect well-being and participation in social life as bladder management often takes time and can cause embarrassment if leaking accidents occur in social settings (Fuseini et al., 2019).

Conservative management is most used to treat bladder problems. Conservative management requires patient education and may also include timed emptying of the bladder. Regular bladder emptying is important to prevent urinary tract infections (UTIs), upper tract damage, and incontinence (Taweel et al., 2015). Current bladder problem management also includes the use of nappies, medication for UTIs, cauterisation, drinking controlled amounts water to maintain a low bladder pressure, and applying pressure on the bladder (Kurze et al., 2022; Pilusa et al., 2020; Paholo et al., 2018). Normal/reflex emptying of the bladder is a seemingly more common practice for bladder problems in people with SCI in developing countries (Chen et al., 2016), possibly due to the cost implications associated with catheterization. It is important that we emphasize good bladder health to avoid hospitalisation as secondary health conditions can really disrupt one life (Mashola et al., 2019).

2.5.2 Bowel problems

Bowel problems are also a common SHC in people with SCI (Emmanual, 2019). Similarly to bladder problems, bowel problems occur as a result of damage to the ANS, hence the loss of

control of these pathways cause the dysfunction to occur (Henke et al., 2022). Bowel problems are also diagnosed through careful examination and establishing the level of the lesion, the severity of the injury and whether it is complete or incomplete (Hughes et al., 2015). The estimated prevalence of bowel problems is between 60 and 80% (Krassioukov et al., 2010; Pavese et al., 2019; StrØm et al., 2022). The types of bowel problems depend on the level and severity of the lesion and they include constipation, fecal incontinence, impaction, megacolon, hemorrhoids, rectal bleeding, prolapse, and formation of anal fissures in some cases abdominal pain (Emmanual, 2019; Lynch et al., 2001). Bowel problems are not fully understood as there is no one size fits all picture and symptoms differ from person to person depending on the level, type and severity of the lesion (Hughes, 2014). Some challenges associated with bowel problems can be attributed to the amount of time required for bowel care, this has a negative impact on quality of life, and participation in social life as it takes time away from other areas of one's life (van der Meer et al., 2017, Mashola et al., 2020).

Most people living with SCI have bowel problems and the role of a healthy bowel is to store feces and to empty at suitable times. To manage bowel problems, it is recommended that people living with SCI follow a bowel routine program (Hughes, 2014). A successful bowel management routine program should ensure that all aspects are covered, this includes methods on how to facilitate bowel evacuation, diet as well as how to manage complications such as constipation using various assistive agents and abdominal massage and even exercise (Hughes, 2014; Krassioukov et al., 2010). The management of bowel problems, and in particular, constipation that is so common in SCI, has remained unchanged for several decades (Kraasioukov et al., 2010). If conservative methods fail, surgical interventions such as colostomy are important options for people living with SCI to know (Krassioukov et al., 2010).

2.5.3 Sexual Problems

Sexual problems are drastically affected after SCI (Park et al., 2017; Pavese et al., 2023). Spinal cord injury affects many areas of a person's life including their sexual function. Sexual health is broadly defined as a state of physical, emotional, mental, and social wellbeing in relation to sexuality; it is not merely the absence of disease, problems, or infirmity (WHO, 2006). The reported prevalence of sexual problems is estimated between 38% -88% and are higher amongst

men than women (Hajiaghababaei et al., 2014; Callaway et al., 2015; Park et al., 2017; Madasa et al., 2020). Though the prevalence seems to vary between male and female counterparts, the impact of sexual problems is significant and complex as it involves many different domains that affect mental health and overall relationship satisfaction (Pavese et al., 2023).

Problems related to sexual health that people with SCI experience include difficulty with sexual arousal, erection, lubrication, and reaching orgasm (Hess et al., 2012; StrØm et al., 2022). Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination, and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected, and fulfilled (WHO, 2006).

Sexual problems affect various aspects of one's life including physical, mental, and social aspects. Immediately after a SCI, most patients focus on their physical function. However, when they eventually accept their injury, dealing with sexuality is also an important step in the rehabilitation process (Hagen, 2015). The effect of SCI on sexual function is often worsened by SHCs such as neurological disorders, bladder and bowel management, spasticity, pain, and low self-esteem. If it is a lesion-related problem it can also influence sexual activity, satisfaction, and sexual response (Lombardi et al., 2010). The consequences of SCI on sexual health may include reduced fertility in men and in the event of a possible pregnancy, autonomic dysreflexia could occur as a complication (Pavese et al., 2023).

The management strategies currently employed for sexual health problems included emptying the bowel and bladder before sexual intercourse, sexual enhancement pills and finding the right sexual positions. These are echoed in studies by (Aikman et al., 2018). There is certainly a need to strengthen sexual health care to improve their overall quality of life in people living with SCI to boost their sense of self and find fulfillment in their intimate relationships (Pilusa et al., 2021). Incorporating peer support groups where individuals can openly discuss their sexual problems and gain from other people with SCI on their sexual experiences can help build self-esteem (Joseph et al., 2016). Secondly, there is a need to ensure people with SCI have access to medication and overall sexual counseling that can help them manage sexual health problems (Pilusa et al., 2022). Such initiatives can address long-term care needs related to sexual health problems to ensure that people with SCI are more knowledgeable on sexual health issues and

how to navigate them. It is necessary that throughout the rehabilitation process, screening for sexual health problems is conducted and this could possibly be done as standard procedure at routine check ups for people with SCI who are sexually active. Embedding sexual health in the rehabilitation care for people with SCI can ensure that individuals with SCI are empowered with sexual health information, reproductive health, and safe sex education (Giurleo et al., 2022). It is important to note that most of the evidence regarding sexual health issues and sexual health education in SCI is from America and Canada thus there is a strong need for more context-based studies. These findings would not be relevant to the South African context as we are not a first world country like America or Canada. Our demography is vastly different, many people living with SCI are unemployed, we also face challenges of inaccessibility to healthcare services and discriminatory belief systems and attitudes (Maart et al., 2013).

Secondary health conditions (SHCs) have been associated with poor health outcomes and increased hospital stay due to the difficulties in managing them (Joseph & Wikmar, 2016). There may be instances that an individual with SCI may refrain from various social and daily activities due to the difficulty of managing SHCs, for example, the fear of bladder or bowel-related accidents. In a study by Piatt et al., (2016), conducted in the United States, when examining the impact of problematic secondary health conditions, 75% identified that the primary problem had a significant impact on social participation and 64% identified it significantly impacted daily life. Secondary health conditions affect overall health and wellbeing (Pilusa et al., 2021) often leading to re-hospitalisation and sadly in some cases, death (Mashola et al., 2019; Madasa et al., 2020).

2.6 Health interventions for SCI

Spinal cord injury is a lifelong injury that needs support to ensure good wellbeing, quality of life and decreased risk for SHCs. Globally there are many standard SCI care models with regards to general SCI care and not prevention of SHCs specifically. A scoping review on SCI care delivery highlighted different types of care models that have been implemented in high income countries such as transitional rehabilitation, independent living, agency care and specialised home-based care (Ho et al., 2021). In South Africa there is no standard model of care for SCI. Pilusa et al., (2022) proposed prevention model of care for SHCs in SCI. The proposed elements of the model

included patient centered care, access to health and rehabilitation care, promoting health, access to medicine and ensuring that health professionals are skilled to care for people with SCI (Pilusa et al., 2022). The proposed model or the elements of the model have not been tested. There is aneed for research to implement and test this model of care.

One of the key components for supporting people with chronic conditions is ensuring that they are empowered with health information. Health information is core to promoting health and enabling an individual to take over their health (WHO, 1998). In addition, empowering patients is part of rendering a patient centered care (Hudon et al., 2012). A study by Evadone et al., (2018), looked at whether education on SHCs following SCI was successful in promoting healthier outcomes such as prevention for SHCs and QoL. The results of this study painted a mixed picture, because although health education improved pressure sore prevention, it did not improve UTI prevention. There was no correlation in this study between the number of classes attended and the health outcomes. (Evadone et al., 2018). The study findings highlighted importance of correct timing, method of delivery, and the approach to education. This tells us that although health education is very important in raising awareness and preventing complications of SHCs, understanding the needs of the patients is critical. This study will look to employ the model of care proposed by Pilusa et al., (2022), looking to approach the education aspect for people with SCI and deliver based on their needs. Secondly, QoL was not affected by the health education in this study, thus it is important that people with SCI are continually encouraged to take control of their life (Evadone et al., 2018).

Examples of studies that used multiple strategies in SCI care are studies by Hossain et al., (2020) and Chishtie et al., (2018). The study by Hossain et al., (2020) conducted in Bangladesh included home visits, and self-care strategies which were phone-based for two years after discharge from hospital. However, the study found that a community-based model of care did not prevent SHCs and improve QoL in the two years after discharge from hospital. Some of the reasons for the failure of the interventions were linked to poverty, lack of employment opportunities, societal attitudes, and inaccessible environments (Liu et al., 2020). Similarly, a study by Chishtie et al., (2018), conducted in Pakistan, looked at preventing pressure sores amongst people with SCI using a community-based rehabilitation approach, focusing on preventative education tailored for the patients, peer support and home visit. The intervention

was effective in preventing pressure sores (Chishtie et al., 2018). The success of this intervention could have been due to the fact that the intervention was tailored, based on the patient's needs. To contextualise this, we hope to achieve the same success in our study as we will be tailoring our health intervention plan based on the needs of people with SCI which will be identified through a qualitative study design.

2.7 Conclusion

In this chapter literature on causes and prevalence s of SCI was reviewed. In addition, SHCs such as, bowel, bladder, and sexual problems in SCI as well as management strategies were reviewed. Secondary health conditions are life changing and extremely impactful on the mental health and quality of life of people living with SCI. Therefore, understanding people with SCI and their experiences of SHCs as well as their long-term needs. This can initiate better conversations between people with SCI and health professionals around seemingly taboo topics such as sexual problems and may help develop not only prevention strategies, but holistic, all-inclusive self-management and coping strategies that will enhance mental health and quality of life in people living with SCI.

In the next chapter, the methodology will be presented.

CHAPTER 3

Methodology

3.1 Introduction

This chapter will outline the methodology and the methods which were employed in this study. Further outlined are the study setting, study design and study participants. In addition, this chapter describes the data collection tool and outcome measures, the study procedure, methods used to collect the data as well as analysis of the statistical data and ethical clearance considerations.

3.2 Study Design

This study employed a mixed method approach, quantitative and explorative qualitative study design. This type of study combines elements of quantitative and qualitative research to answer the research question (Morse, 2016). Mixed methods can help you gain a more complete picture than a standalone quantitative or qualitative study, as it integrates benefits of both methods.

Mixed methods research is often used in the behavioral, health, and social sciences, especially in multidisciplinary settings and complex situational or societal research. The selected design is inexpensive, time efficient and does not require expensive equipment or settings (Morse, 2016). Valuable information may be gathered to help guide future prospective or experimental studies (Vassar and Holzmann, 2013).

3.3 Study Setting

The study was based at Siletha Ithemba, a Non-Profit Organization (NPO) in Manguzi, KwaZulu Natal. The NPO was started in 2013, but only formally registered as an NPO in August 2020. The NPO was initiated by a Physiotherapist at Manguzi Hospital to bring hope to people with disabilities. The NPO strives to connect people to strengthen community networks, provide mentorship or practical advice and advocate for the rights of people with SCI by, for example raising awareness. The NPO also works closely with public rehabilitation teams to provide new staff and students with practical examples of the challenges faced by people with SCI. The NPO is run by seven wheelchair users who are known as peer supporters, one qualified occupational therapy technician, a physiotherapist, an occupational therapist and 1 occupational therapy

assistant. There are currently forty wheelchair users registered with the NPO with various disabilities, thirteen of them have SCI. All thirteen were invited to participate in the study, one person did not meet the inclusion criteria.

The focus of this NPO is to provide psychosocial support to patients, offer wheelchair skills, help families and patients overcome environmental barriers, educate patients on pressure care, as well as bowel and bladder. The NPO also acts as a medium of contact between the hospital and patients with disabilities, as well as act as an alert system for the Manguzi therapy staff with regards to high-risk patients. The NPO works closely with the Manguzi Hospital, and they have bi-monthly meetings with the therapy staff for a general meeting and a case discussion in which patients seen in the past month are discussed, ideas are shared, and it becomes a learning platform.

Other services rendered include home visit, occupational and physiotherapy, telephonic support from their three peer supporters. The peer supporters also act as role models and share their experiences on how they have overcome their barriers in the community. Peer supporters assist the Manguzi Hospital rehabilitation staff at seating clinics by servicing wheelchairs and offering peer support to patients with disabilities. The peer supporters also serve as a first point of contact for wheelchair maintenance and consumables refill.

I specifically chose this NPO because it is based in a rural setting and the NPO works very well with the district hospital. The NPO has an existing peer support group in place. Hence the patient centered approach is likely to succeed if there is already a support system in place to work from.

The whole study was divided into two parts. Part A – Qualitative study and Part B - Quantitative study. The results from part A were used to develop the intervention in part B.

PART A: Qualitative study

The qualitative study aimed to address the following objectives:

1. Explore the experiences of bowel and bladder problems as well as sexual health in people with spinal cord injury (SCI).

2. Identify long-term care needs related to bowel, bladder, and sexual problems in people with SCI.

3.4 Study Participants

The study included community dwelling people with SCI who are served by the Siletha Ithemba NPO.

3.4.1 Inclusion Criteria

1. Diagnosed with SCI, irrespective of the level, duration, and severity of the lesion.
2. Above 18 years of age.

3.4.2 Exclusion Criteria

People with SCI and an associated head injury, and other neurological conditions as I specifically wanted to look at the effects of SHCs such as bowel, bladder and sexual problems on mental health and QoL without any other factors associated with head injuries and/or other neurological conditions.

3.4.3 Sample Size

Community dwelling people with SCI who are served by the Siletha Ithemba NPO who met the inclusion criteria were invited to participate in the study. Purposive sampling was used, which is a technique widely used in qualitative research for the identification and selection of information rich cases related to the area of interest (Palinkas, et al. 2015). Peer supporters along with NPO physiotherapist at the NPO helped identify possible participants based on inclusion and exclusion criteria.

3.5 Data Collection Tools

A semi-structured interview approach was used to elicit relevant data for qualitative analysis (Lofland, 1971). Semi-structured interviews gave participants more room to answer in terms of what is important to them (Miles & Huberman, 1994; Strauss & Corbin, 1998).

An interview guide was developed by the researcher to facilitate face to face semi structured interviews (Appendix 5). The interview guide had two sections. Section A: Was to collect demographic data. Section B: Included open ended questions based on the study aim covering several topics: experience of bowel and bladder problems; sexual problems, management and prevention of these SHCs problems and longterm needs.

3.6 Procedure

Once ethical clearance was received, a pilot study and the subsequent main study data collection were done. These events are described below.

3.6.1 Pilot Study

To ensure and improve the practicality, familiarity, efficiency and quality of the demographic data form and overall study procedure (Thabane et al., 2010), a pilot study was conducted at Manguzi Hospital during the week of 18 April 2022. The researcher used the guided interview and practiced the questions with the peer supporters who were assisting with the interviews, 2 of the 3 peer supporters live with SCI, one fit the inclusion criteria and 1 did not. The peer supporters were also well known to the study participants to ensure effective communication and understanding. No amendments needed to be made to the demographic data form or to the study in its entirety.

3.6.2 Main Study

As each participant provided written consent to perform the study, suitable arrangements were made for the researcher and research assistant (peer supporter) to travel to each participant's home to conduct the interview. The role of the assistant was to conduct the interview in the participants home language. The interviews occurred between the weeks of 18 – 23 April 2022. On the agreed upon date and time, the researcher and research assistant travelled to the respective participants homes to conduct semi-structured interviews for data extraction. The interviews were conducted in the language that the participants were comfortable in (12 in isiZulu and one in Sesotho). All the interviews were audio recorded using an audio recorder as well as a cellphone using the voice recorder app for back up.

3.6.3 Data analysis

The demographic data forms were inputted onto a Microsoft Excel spreadsheet for further analysis. The interviews were transcribed verbatim and then translated into English by a research assistant. The accuracy of the manual transcripts was checked by the researchers who read and reread the transcripts and checked them against notes taken during the interviews. The data was analysed manually and using MAXQDA version 2018.2. We analysed the data following the content analysis steps described by Erlingsson and Brysiewicz (2017): reading and reading each transcript to gain a sense of deeper understanding and to become familiar with the content of the transcripts. Thereafter, separately the researchers coded the transcripts inductively, identifying meaning units. Similar codes were sorted into categories and subcategories and the overarching themes that related to the experience of sexual health, bladder and bowel problems were identified.

Debriefing sessions were held throughout the process to discuss and compare the findings.

PART B: Quantitative design

The quantitative study aimed to address the following objectives:

1. To assess the effectiveness of the health program for bowel, bladder, and sexual problems on quality of life (QoL).
2. To assess the effectiveness of the health program for bowel, bladder, and sexual problems on mental health in people with spinal cord injury (SCI).

Study design

A Quasi-Experimental Pretest–Post test Design was used. An advantage of a pre-test and post-test study design means that there is testing of a dependent variable before and after an intervention with an independent variable (Stratton, 2019).

3.7 Study Participants

The study included community dwelling people with SCI who are served by the Siletha Ithemba NPO.

3.7.1 Inclusion Criteria

1. Diagnosed with SCI, irrespective of the level, duration, and severity of the lesion.
2. Above 18 years of age.

3.7.2 Exclusion Criteria

People with SCI and an associated head injury, and other neurological conditions.

3.7.3 Sample Size

Community dwelling people with SCI who are served by the Siletha Ithemba NPO that met the inclusion criteria were invited to participate in the study. Purposive sampling was used, which is a technique widely used in qualitative research for the identification and selection of information rich cases related to the area of interest (Palinkas, et al. 2015). Peer supporters helped select participants based on inclusion and exclusion criteria.

3.8 Data Collection Tools

The data collection tool included demographic data (Appendix 6), questions on QoL (Appendix 7) and mental health (Appendix 8).

3.8.1 Quality of Life (Appendix 7)

The WHOQoL-BREF was used to measure quality of life before and six weeks after the health program (AbilityLab, 2020). This questionnaire consists of 26-items that measure QoL. It has four domains, namely: physical, psychological, social relationships and environment (Hill et al. 2010). The WHOQoL-BREF questionnaire showed high reliability (Cronbach's $\propto = 0.74–0.87$). The questionnaire is scored by adding up the scores of each domain and similarly the total score is calculated by adding the domains.

Items are rated on a 5-point scale (1 being the lowest and 5 the highest) to determine an item score (AbilityLab, 2020). The mean score for each domain is calculated resulting in a mean score

per domain that is between 4 and 20, this mean domain score is then multiplied by 4 in order to transform the domain score into a scaled score. A higher score indicates a higher QoL (AbilityLab, 2020).

3.8.2 Mental Health (Appendix 8)

Short form-12 (SF-2) questionnaire was used to assess mental health of people with SCI (Whitehurst, et al 2014). SF-12 is a self-reported outcome measure assessing the impact of health on an individual's everyday life. It is often used as a quality-of-life measure. The SF-12 is a shortened version of its predecessor, the SF-36, which itself evolved from the Medical Outcomes Study (Ware, 1995). The SF-12 was created to reduce the burden of response and uses the same eight domains as the SF-36.

When compared to the SF-36, the SF-12 scores are similar. The way the scoring is calculated is that each item is scored on a 0 to 100 range so that the lowest and highest possible scores are 0 and 100, respectively (Rand Corporation, 2021), the scores represent the percentage of total possible scores achieved. Items in the same scale are then averaged together to create the scale scores (Rand Corporation, 2021). Items that are left blank (missing data) are not considered when calculating the scale scores. Hence, scale scores represent the average for all items in the scale that the participant answered (Rand Corporation, 2021).

The SF-12 has good sensitivity and specificity relative to other screening tools for depression and other mental disorders (Berwick et al., 1991).

3.9 Procedure

All the three peer supporters were trained by the researcher on the questionnaires and how to administer them. After ethical clearance and permission was granted to conduct the study, the people with SCI affiliated to the NGO were recruited to participate in the study. The peer supporters from the NPO called the people with SCI and explained the purpose of the study. Informed consent as well as their contact numbers was sought from all the individuals with SCI. Questionnaires were then administered telephonically in a language understood by the

participants (IsiZulu) a week before the health program and again six weeks after the health program.

3.10 Pilot Study Procedure

1. The questionnaires were piloted between the researcher and research assistant with SCI to ensure that questions were clear.
2. The trained research assistant administered the questionnaires which included demographic data, WHOQoL-BREF and SF-12 questionnaires respectively. These were conducted telephonically. The aim of the study and the study procedure was explained in the invitation and written consent was obtained for participation.
3. All recommendations from the research assistant with SCI were noted and incorporated in the main study.

3.11 Main Study

The information gathered from the semi-structured interviews informed the content for the health education intervention pertaining to bowel, bladder and sexual problems experienced by people with SCI.

3.11.1 Intervention Information

The health intervention program included (Appendix 9): A consultation with a rehabilitation doctor for a baseline assessment on general health including a bowel and bladder check-up. The baseline assessment included the following:

- kidney ultrasound
- blood pressure

A group health education by health professionals (physiotherapist, dietician, and sex counsellor) was conducted at Manguzi Hospital. The health education covered topics on bowel, bladder, and sexual problems, how to manage them, importance of a healthy diet and recommended practices. Follow-up care was done on a weekly visitation basis by the peer supporters to ensure

compliance to new recommended practices. Questionnaires were re-administered six weeks after intervention.

3.12 Statistical Analysis

The data collected was analysed according to the study objectives. Data was captured on Excel. StataSE version 17.0 was used to analyse data, significance was set at p value ≤ 0.05.

Table 3.12: Study Objectives and the Associated Type of Statistical Analysis Performed

Objectives	**Outcome Measures**	**Data type**	**Analysis method / statistical test**
	Demographic data	Ordinal Categorical	Median, mean, std deviation. Frequencies and percentages
To assess the effectiveness of the health program for bowel, bladder, and sexual problems on quality of life (QoL)	WHOQoL – BREF	Categorical	Paired t-test
To assess the effectiveness of the health program for bowel, bladder, and sexual problems on mental health in people with spinal cord injury (SCI)	SF-12 Questionnaire	Categorical	Paired t-test

3.13 Ethical Considerations

Ethical clearance was granted by the University of the Witwatersrand's Human Research Ethics Committee (clearance certificate number: M210813; 03 March 2022 (Appendix 12). This

research study is registered with the National Health Research Database: KZ_202201_018 (Appendix 11). Permission to conduct the study in KZN at Manguzi Hospital was granted (Appendix 10). All the participants were given a study information sheet (Appendices 2a and 2b) and consent to participate was granted (Appendices 3a – 4b).

To ensure patient confidentiality, data was collected with each participant being assigned a unique case number. No identifiable data was included on the data collection form. The Microsoft Excel spreadsheet used to code information from the data collection form was password protected with access limited to the researcher and the direct study supervisors.

Considering the global COVID-19 pandemic, precautions were undertaken to ensure the safety of the researcher and participant. This included the washing of hands and sanitisation of all stationery before and after use. In addition, the researcher, research assistant and participant wore masks and sat 1.5M apart for interviews. The downside of wearing masks during interviews hindered collection of both verbal and non-verbal expressions, it also took away the element of personal interaction.

Chapter 4 will present the results for experiences of sexual problems and the related long-term needs among people with spinal cord injury.

CHAPTER 4:

Sexual problems experienced by people with spinal cord injury.

In this chapter the results for the sexual problems will be presented. This chapter is written as a manuscript according to the journal guidelines. The study objectives were:

1. To explore the experience of sexual problems as well as sexual health in people with spinal cord injury (SCI)

2. To identify long-term care needs related to sexual problems in people with SCI.

Title	Sexual health problems in people with spinal cord injury in Manguzi, KwaZulu Natal: Experience and long-term care needs
Journal	African Journal of disability
Status	Under review
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Author contribution

	Lauren Tomes	**Sonti Pilusa**
Conceptualization	√	√
Method	√	√
Data analysis	√	√
Resources	√	
Manuscript writing draft	√	
Manuscript writing review and editing	√	√
Supervision		√

Title: Sexual health problems in people with spinal cord injury in Manguzi, KwaZulu Natal: Experience and long-term care needs

Abstract

Background: Sexual health problems are one of the secondary complications affecting people with spinal cord injury (SCI). However, studies on the experience of sexual health problems and long-term care needs among people with SCI in rural South Africa are scarce.

Aim: This study aimed to determine the following:

1. To explore the experience of sexual health problems in people with spinal cord injury.
2. Identify long-term care needs related to sexual health problems.

Method: This study used an explorative qualitative study design. Twelve people with SCI based in Manguzi KwaZulu Natal were interviewed. All the interviews were transcribed verbatim and analysed using thematic analysis.

Results: The main theme for the experience of sexual health problems was "Dissatisfaction". The categories were: types of sexual health problems, factors influencing sexual activity, the impact of sexual problems, and the management of sexual health problems. The long-term care needs for sexual health problems included the need for medication (sexual enhancement pills) and information on how to manage sexual health problems.

Conclusion: The findings show that sexual health problems are worrisome and negatively impact relationships and self-image. Holistic interventions are needed to address sexual health problems among people with SCI.

Implications:

Practice: Sexual counselling and education should be part of in-patient and out-patient rehabilitation care for people with SCI.

Research: Implementation of research on the effects of patient education on sexual health interventions among people with SCI is recommended.

Keywords: Spinal cord injury, sexual problems, long-term care needs

Introduction:

Spinal cord injury (SCI) is a chronic disabling condition that has long-term effects on an individual's health and well-being. In addition to the impairments related to SCI, secondary complications such as pain, pressure sores, bowel and bladder, and sexual health problems are prevalent (Pilusa, Myezwa & Potterton, 2021; Joseph & Wikmar, 2016). A critical area that doesn't receive enough attention in SCI care, even though it affects the quality of life is the area of sexual health (Courtois & Charvier, 2015). The World Health Organization (2015) defines sexual health as a "state of physical, emotional, mental and social well-being in relation to sexuality; not merely the absence of disease, problems or infirmity". People with disability are wrongly considered to be asexual, thus the area of sexual health is neglected (Ganle et al., 2020).

Sexual health problems are common among people with SCI. The prevalence of sexual health problems is estimated to be between 38-88% higher among men than women (Hajiaghababaei et al., 2014; Callaway et al., 2015; Park et al., 2017; Madasa et al., 2020). Sexual health problems experienced by men include decreased libido, erectile problems, ejaculatory problems, pain during sex, and anorgasmia (Aikman, Oliffe, Kelly & McCuaig, 2018). While women include altered sexual desire and arousal, altered genital sensation, altered vaginal lubrication, altered vaginal accommodation, satisfaction, pain, and orgasm (Giannopapas, V; Pneumaticos & Vlamis, 2021). Sexual health problems in people with SCI are caused by the disruption in the motor, sensory and autonomic pathways (Courtious et al., 2015). Sexual health problems should be anticipated and regularly screened for, given the anatomical and physiological disruptions caused by SCI.

There are many factors that can influence one's sexuality with SCI, they can be intrinsic or extrinsic such as sexual health problems, age, duration of SCI, self-image, level, and severity of SCI, pre-injury sexual experiences and attitudes, and openness to sexual experimentation (Aikman et al., 2018; Hess et al., 2012). In addition, the presence of SHCs such as pain, spasms, depression, bowel and bladder problems, and autonomic dysreflexia affect sexual satisfaction (Giannopapas et al., 2021). Extrinsic factors influencing sexual health include intimate relationship status, culture and masculinity norms, incorrect perceptions that people with disabilities are asexual, and poor access to sexual education (Giannopapas et al., 2021; Aikman et al., 2018). Rehabilitation professionals must take note of these multiple factors when

developing sexual health interventions to minimize the impact of sexual health problems on well-being.

Sexual health problems can impact mental health and relationships. The change and anticipation of the loss of sexual interest may impact a person's self-esteem and sense of value as a sexual being (Callaway et al., 2015; Courtoius et al., 2015; Giurleo et al., 2022). A study by Callaway et al., (2015), looked at community integration outcomes of people with spinal cord injury (SCI) and found that there was low home integration of people with SCI and that their intimate relationships suffered because of it as well. Individuals with SCI fear losing intimate partners and not being able to satisfy the partners' sexual needs (Fuseini et al., 2019; Pilusa et al., 2021). Since sexual health is an integral part of life, addressing sexual health problems should be part of SCI rehabilitation care (Giurleo et al., 2022). The rehabilitation team members must encourage open conversations between the person with SCI and their partners and support open communication and experimentation.

Although sexual health problems are one of the priority secondary complications, sexual problems receive minimal health care attention. Brinkhof et al., (2016) study on the prevalence, severity, co-occurrence, and treatment of secondary complications in people with SCI found that 85.5% of sexual health problems were not treated. Sexual health care practice is often minimal, with health professionals feeling inadequate to address sexual health problems (Giurleo et al., 2022). Other barriers affecting the provision of sexual health education in rehabilitation settings include lack of time, perceptions that it is someone else’s job, conflicting personal beliefs surrounding sexuality, and assumptions that the patients are not ready (Giurleo et al., 2022; Aikman et al., 2018). People with SCI need support to manage sexual health problems through counseling, education, and peer support. Thus, the study aimed to explore the experience of sexual health problems in people with spinal cord injury and identify long-term care needs related to sexual health problems.

Methodology

Study Design

This study employed an explorative qualitative study design to understand the experience of sexual health problems and related long-term care needs.

Study Setting

The study was based in a rural setting, Manguzi, Umkhanyakude district KwaZulu Natal. Manguzi has a high employment rate, poor housing, and people with disabilities struggle to travel to health care services because of the uneven terrain, inaccessible transport system, and the high cost of public transport. The researcher worked with Siletha Ithemba, a Non-Profit Organization (NPO) based in Manguzi to identify potential participants. Siletha Ithemba NPO works closely with the therapist at Manguzi district hospital to provide comprehensive care for clients with disabilities and their families. The services provided by the NPO include psychosocial support, wheelchair skills, health education on secondary complications, home visits, occupational and physiotherapy, and peer support.

Study Participants

The study included community-dwelling people with SCI whom the Siletha Ithemba NPO serves. The inclusion criteria were only people with SCI diagnosed with SCI, irrespective of the level, duration, and severity of the lesion and above 18 years of age. Purposive sampling was used to recruit people with SCI. Twelve people with SCI were invited to participate in the study.

Data Collection Tools

Semi-structured face-to-face interviews were used to elicit relevant data for qualitative analysis giving the participants more room to share their experiences (Miles & Huberman, 1994; Strauss & Corbin, 1998). The interview guide developed by the researcher was used to facilitate face-to-face semi-structured interviews. The interview guide included open-ended questions on the experience of sexual health problems, how they were managed, their impact and long-term care needs related to sexual health problems.

Data collection procedure

Once ethical clearance was received, a pilot study and the subsequent main study data collection were conducted. The pilot study's purpose was to ensure and improve the practicality, familiarity, efficiency, and quality of the demographic data form and overall study procedure

(Thabane et al., 2010). The pilot study was conducted with a peer supporter with SCI, who also assisted with data collection. No amendments were made to the interview guide or the study procedure. As each participant provided written consent to perform the study and permission to audio record the interview, suitable arrangements were made for the researcher and research assistant to visit the participants. The interviews were conducted in the language that the participants were comfortable with (11 in isiZulu and one in Sesotho). The researcher is not fluent in isiZulu or Sesotho hence the research assistant was relied on for translation. All the interviews were audio recorded using an Andowl professional recorder. Data collection occurred 19-22 April 2022. The interviews lasted between 30 to 60 minutes.

Data analysis

The demographic data forms were inputted onto a Microsoft Excel spreadsheet for further analysis. The recorded interviews were transcribed verbatim and translated into English. All the transcripts were read several times by the researcher. Manual coding was conducted on two transcripts by the researchers separately. The findings were discussed, and a coding framework was developed and used to code the rest of the transcripts. Debriefing sessions were held throughout the process to discuss and compare the findings.

Rigor

To ensure credibility, the researcher kept a journal to capture notes on the research process, personal reflections, and observations. All interviews were audio recorded to ensure the accuracy of the interpretation of the experiences of the participants and debriefing sessions throughout the research process, findings, and data analysis. To ensure dependability, an audit of the entire research process will be kept, and a detailed description of the data collection, analysis, and interpretation was described for transferability, the context and the methodology were explained in detail.

Ethical Clearance

Ethical approval of this study was approved by the Human Research Ethics Committee of the University of the Witwatersrand (approval number M210813) and registered with the South African National Health Research Database (reference KZ_202201_018). Manguzi hospital and Siletha Ithemba NPO granted permission to use the study site for data collection. All the

participants formally consented and signed informed consent forms to participate in the study. During the data analysis all data was coded and stored on a password-protected laptop. To ensure anonymity, the quotes were labelled as P1 and gender etc.

Results

Twelve people with SCI were interviewed. The majority 83% (n=10) were male, single and unemployed. The age range was 28-60 years, the mean age was 43.83 and the standard deviation was 11.16. The years since injury ranged from 3-33 years, the mean 13.33 and the standard deviation was 8.96. All the participants experienced secondary complications. Refer to Table 4.1

Table 4.1: The participants' demographic and injury profile

Participants	1	2	3	4	5	6	7	8	9	10	11	12
Age yrs.	28	41	51	34	57	30	55	51	55	40	46	38
Date of injury (years)	3	19	10	9	20	3	33	18	20	13	5	7
Level of injury	T8	L4	L5	L3	L1	L3	T12	L2	T12	C4	T12	T12
Type of injury	Paraplegic Incomplete	Paraplegic Complete	Paraplegic Incomplete	Paraplegic Incomplete	Paraplegic Incomplete	Paraplegic Incomplete	Paraplegic Incomplete	Paraplegic Incomplete	Paraplegic Incomplete	Quadriplegi a Complete	Paraplegia Incomplete	Paraplegia incomplete
Cause of injury	Traumatic Stabbed	Traumatic Shot	Non-traumatic TB spine	Traumatic Gunshot	Non-traumatic TB spine	Traumatic Stabbed	Traumatic Gunshot	Traumatic Gunshot	Non-traumatic TB spine	Traumatic (MVA)	Traumatic Stabbed	Non-traumatic TB spine
Education level	High School Grade 11	High School Grade 10	No schooling	High School Grade 11	No schooling	Matric and post matric computer literacy	Primary school Grade 4	High School Grade 10	Primary School Grade 4	No schooling	High School Grade 10	High School Matric
Marital status	Unmarried	Married	Unmarried	Unmarried	Unmarried	Unmarried	Unmarried	Unmarried	Unmarried	Married	Unmarried	Unmarried
Employment	Unemployed	Employed	Unemployed	Unemployed	Unemployed	Unemployed	Unemployed	Unemployed	Unemployed	Self employed	Unemployed	Unemployed
SHCs	Pain Spasms Flaccid bladder	Pain Pressure sore	Pain Spasms Bowel problems Bladder problems Contractures	Pressure sore Spasms Bowel problems	Pain	Pressure sore Pain Contracture	Pain Spasms	Pain	Pressure sore Spasms Contracture	Pain Autonomic dysreflexia Fits Pressure sores	Spasm Pain Bowel problems	Pain

Theme and categories

"Dissatisfaction" was the main theme that emerged around the experience of sexual problems. The categories were:

1. Types of sexual health problems.
2. Factors influencing and sexual activity.
3. Impact of sexual health problems.
4. Management of sexual health problems.

All the participants experienced sexual health problems and there was a sense of dissatisfaction as reported by these participants.

"I often practice oral sex just to satisfy my wife, but I do not perform it daily for obvious reasons that there is no satisfaction on my side, and it does not make me feel happy" (P9 male)

"I won't lie, it (sex) is not good. I do it (sex), but I don't get satisfied. Sometimes a woman can visit me expecting to have sex, but it just won't happen. It is very bad" (P6 male)

1. Types of sexual health problems experienced.

The reports related to sexual health problems were mainly from male participants. The participants experienced different types of sexual health problems: erectile problems, poor sexual performance and lack of sexual desire:

"I get frustrated when my heart and mind think of sex, but I cannot have an erection since I do not have sexual feelings" (P4 male)

"*My problem on that part (sex), honestly speaking it happens that when I want to have sexual intercourse I experience erectile problems...*" (P2 male)

Some participants felt that their sexual performance was poor:

"*the challenge that I experience is that I cannot perform well"* (P10 male)

While some participants had low or no sexual desire:

"Few months after my injury I was sexually active, and my sexual feelings were in good condition with a sexual appetite. From time to time there were changes in my sexual feelings which resulted to the loss of sexual appetite" (P2 male)

"Erectile problems and low sex drive is another contributing factor for not being 100% fit for sexual intercourse" (P12 male)

The two female participants reported no sexual problems, just that they have not had sex:

"The last time I had sex was the last time you were here, I didn't have sex since my husband had some health problems. But I am fine, I don't have a problem doing it." (P8 female)

"It been 20 years since I last had sexual intercourse with a person I was in love with. I didn't find a boyfriend when I relocated to this place, because of this condition (SCI). They tried to propose love to me, but I told them that I could not have sexual intercourse because of my disability." (P5 female)

They also expressed that they do not need to engage in sex:

"I am old now, they call me granny so its fine." (P5 female)

"I never asked him my sister I don't want to lie. My problem for now is that my soul is troubled because of stress. I don't need it." (P8 female)

2. Factors influencing sexuality.

The perceived factors influencing sexual activity included secondary health conditions, perceptions of disability and relationships, lack of knowledge on sexual health, and partner satisfaction.

2.1 Presence of secondary health conditions.

The presence of secondary health conditions limited some of the male participants such as pain, pressure sores and contractures, bowel and bladder incontinence and emotional issues affected engagement in sexual intercourse.

Presence of pain limited sexual activity as reported by these participants:

"I cannot sleep on the side for a long time because of the pain in the healed pressure sore site. This pain lowers my sexual appetite, it hurts me because I can see that my partner is not sexually satisfied." (P4 male)

"Pain in my legs is the main reason for me to be unable to have sex". (P6 male)

Stiffness of the muscles, spine and legs also limited engagement in sexual activity and caused discomfort:

"My spinal cord is stiff and blocked, which causes discomfort when I try to have sexual intercourse." (P2 male)

"Ever since my disability, I never had sex because my spinal cord and legs are stiff, which makes it impossible for me to have sexual intercourse. My knees and muscles are also stiff and that limits the chance to try having sexual intercourse" (P6 male)

The presence of pressure sores and urinary incontinence also affected engagement in sexual intercourse as expressed by two of the participants:

"I had challenges of urinating by the time I was starting to prove that I can have sexual intercourse. When I start the foreplay with my partner the urine just flows by the time I get sexual arousal" (P2 male)

"Since I was injured and developed pressure wounds, I realized I would not involve myself in any sexual activities. It was early 2015 when I saw that I have pressure sores, I just chose to put aside my sex life" (P4 male)

2.2 Disability perceptions.

Some participants felt that because they had a disability (SCI) they could not engage in sexual activity.

"I never had sexual intercourse since I became disabled. My condition does not allow me to have sex and my body is not in good condition to have sex, my spine and my legs are not in a good condition." (P6 male)

Some participants expressed that their sexual feelings were impaired due to the injury to the spine and the damaged sexual feelings decreased the desire for sex:

"*From the time I got injured, my sexual feelings were damaged. I never thought about getting back into a sexual relationship. I stayed the whole year with the hope that things will be fine. As time passed, I realized that my sexual feelings are not working."* (P6 male).

"My sexual feelings are damaged and that leads to the absence of sexual appetite." (P12 male)

2.3 Lack of knowledge.

The participants reported a lack of knowledge on sexuality issues and how to manage sexual problems.

*"Essssh I was hopeful that things can be normal like it was before the injury. I can see that I cannot move my legs because I'm disabled, I don't have any idea what I must do regarding sexual intercourse" (*P4 male)

*I do not know the causes of these disturbances on my sexual feelings in my body" (*P1 male)

2.4 Partner satisfaction.

Making the partner happy motivated some participants to engage in sexual activity even if they did not enjoy it.

"*Although I don't have the feeling of enjoyment when I have sexual intercourse on my mind, there is that thing that my partner is happy and there are children which we made after the spine*

injury; that makes me happy although I don't have the feeling of enjoyment when I have sex" (P2 male)

"I often practice oral sex just to satisfy my wife, but I do not perform it daily for obvious reasons that there is no satisfaction on my side, and it does not make me feel happy" (P9 male)

3. Impact of sexual health problems.

The participants expressed how sexual health problems affected their mental health, relationships, and self-image. Mental health impact was expressed as frustration, stress, sadness, and fear:

"It (sexual problems) affects me very bad because sex is a source of happiness for everyone." (P12 male)

"*I feel stressed about the fact that I cannot have sexual intercourse with my wife to satisfy her sexual needs"* (P4 male)

Intimate relationships were also affected negatively by sexual problems. The participants felt that they could not satisfy their partners' sexual desires.

"Sexual problems led to me losing hope in relationships and realizing that there is no need for a relationship because we won't do anything (sex) with a person I will fall in love with." (P1 male)

"*My wife is healthy and has sexual feelings as a human being, most painful thing from her side is that she needs sexual intercourse, but I am unable to provide that need to her."* (P9 male)

As a result of not being able to satisfy the sexual needs of their partners, some participants felt that they were not fully human:

"It affects me badly because sex is the source of happiness for everyone. If I can't have sex, it is like I am living an incomplete life, I am not a complete human being. Your girlfriend cannot take you as a living person" (P4 male)

Some participants lost intimate partners because they felt they could not satisfy them, *"My previous sexual relationship ended because I could not satisfy my partner in bed, so we decided to go our separate ways."* (P5 female)

4. **Management of sexual health problems.**

The participants used several strategies to manage sexual health problems such as medication, cheese, and bowel and bladder first before sex.

The medication used to manage sexual health problems included stimulants and pain medication.

"Sometimes I take pills (sexual stimulants) to boost my sexual appetite and enhance my performance during sexual intercourse." (P12 male)

"Ehhh I manage it… if I meet a girlfriend, I buy some pills to help myself. The problem is that if you get used to the pill, you no longer perform well without it." (P11 male)

Other management practices included managing bowel and bladder problems before engaging in sexual activity:

"After a while, I realized that I must give myself time to visit the toilet every evening, if I push the bowel at the same time the urine comes out. I did that and it helped me a lot, I have to practice this habit to avoid problems when I have sex with my partner". (P2 male)

Ignoring sexual feelings was another strategy used to manage sexual problems:

"*There is nothing I can do. I think about it for almost 5 minutes and then ignore the thoughts as it can end up giving me problems"* (P1 male)

"I stayed single for a long time now I'm used to it; I don't feel anything when I see a man." (P5 female)

One participant used diet (eating cheese) to enhance sexual performance:

"Sometimes I eat cheese; it makes me strong in bed." (P7 male)

Long-term needs related to sexual health problems.

The participants highlighted that they needed information on how to manage sexual health problems.

"Mhhh I think maybe here in this hospital if there could always be people like you to come and talk to us about sexual problems after two months or three months, to come and ask us what must be done and teach us what to do. I think that is what can help." (P11 male)

Participants needed medication to manage pain and sexual stimulants:

"I think doctors can help me with medication or treatment to solve the problem of my sexual feelings." (P9 male)

"I need doctors to give me treatment to help me finish the pain (from healed pressure sore) that disturbs me when I want to have sex." (P2 male)

"Maybe if I can get something like an injection to be able to use it if I will be with a woman." (P11 male)

Some participants did not get the help needed to manage sexual health problems "*The doctor ignored me when I tried to raise the case of my sexual feelings, then promised me that this problem will be attended to very soon. I feel like doctors do not give me enough attention when I raise the problem of my sexual feelings"* (P9 male)

Discussion

This is the first study to the best of our knowledge on sexual health problems in people living with SCI in rural South Africa. This study aimed to explore the experience of sexual health problems in people living with SCI and identify their long-term care needs. Most of the participants were male and most of the responses on sexual health problems were from men. This trend is common as SCI is more prevalent among males (Hess et al., 2012). There were only two female participants in the study and they did not make mention of any sexual health problems only that they have not had sex. The main theme that emerged for sexual health problems was "dissatisfaction". The participants were not satisfied with their sexual health because it made them feel like they were not living a complete life or that they were old and undesirable by the

opposite sex. This finding is similar to previous studies on people with SCI (Callaway et al., 2015; Fuseine et al., 2019). Sexual health problems bring a sense of despair and dissatisfaction for both the individual with SCI and the intimate partner (Pilusa et al., 2021; Callaway et al., 2015). These findings highlight the need for conversations around sexual health, sexual engagement, reproductive health, and safe sex (Giurleo et al., 2022).

The study found that the participants struggled with sexual intimacy and the types of sexual health problems included erectile problems, painful sex, and low sex drive. These types of sexual health problems experienced are common complaints in people with SCI (Taylan et al., 2020; Hess et al., 2012). Men experience problems with the duration of their erection if they do not use interventions to enhance them, whereas women often experience pain during intercourse and a lack of vaginal lubrication (Hess et al., 2012). It is necessary that throughout the rehabilitation process, screening for sexual health problems is conducted. Embedding sexual health in the rehabilitation care for people with SCI can ensure that individuals with SCI are empowered with sexual health information, reproductive health, and safe sex education (Giurleo et al., 2022).

The management strategies employed for sexual health problems included emptying the bowel and bladder before sexual intercourse, sexual enhancement pills, ignoring sexual feelings, and diet. Despite the varied strategies, there were challenges experienced in managing sexual problems such as not feeling satisfied, fear of dependence on medication, and the need for more information and medication (sexual enhancement pills and pills for pain). The findings show the need to strengthen sexual health care to improve their overall quality of life, boost their sense of self and find fulfillment in their intimate relationships (Pilusa et al., 2021). Incorporating peer support groups where individuals can openly discuss their sexual problems and gain from other people with SCI on their sexual experiences can help build self-esteem (Joseph et al., 2016). Secondly, there is a need to ensure people with SCI have access to medication that can help them manage sexual health problems (Pilusa et al., 2022) Such initiatives can address long-term care needs related to sexual health problems to ensure that people with SCI are more knowledgeable on sexual health issues and how to navigate them.

The presence of other secondary health conditions (SHCs) such as pain, and urinary incontinence, affected engaging in sexual activity. Previous studies have shown that secondary

complications can be bothersome and disruptive (Pilusa et al., 2020 & Mashola et al., 2019). Pain is prevalent in people with SCI and is the most devastating symptom that has a ripple effect on mobility and functioning (Fuseini et al., 2019; Mashola et al., 2019; Madasa et al., 2020). Contractures in the lower limbs affect positioning and limit the desired full range of motion required for sexual positions (Taylan et al., 2020). Moreover, people with SCI experience multiple SHCs and some SHCs co-occur (Pilusa et al., 2019 & Brinkhof et al., 2016). For example, pain, bowel, and bladder problems co-occur with sexual health problems (Brinkhof et al., 2016; Park et al., 2017). This shows that when developing sexual health interventions, it is essential to consider clustering SHCs and develop interventions that can also address multiple SHCs.

This study found that sexual health problems affected mental health. The participants expressed fear and stress regarding their partners potentially leaving them because of their sexual problems. Previous studies also reported that people with SCI expressed feelings of stress and hopelessness regarding sexual problems (Fuseini et al., 2019). Interestingly, many of the sexual health problems experienced came from the male participants compared to the two female participants in the study who were disinterested in their sexuality and displayed a level of acceptance that they did not need to engage in sexual activity or be in an intimate relationship. Studies have found that most women believe that they have a passive role in sexual intercourse and this adversely affects their sexual functioning (Hajiaghababaei et al., 2014). Collaborative care is needed when managing sexual health problems to address all health and well-being domains.

Similar to previous studies, participants highlighted how their sexual health problems affected their intimate relationships. Many of them expressed that they feel “incomplete” as intimacy is an important part of relationships and feel inadequate without sex. Sex is essential to ‘normal’ adult functioning, and for men in particular (Terry et al., 2012). A study by Fuseini et al., (2019) based in Ghana explored lived experiences of persons living with SCI and reported how the participants experienced feelings of disappointment in fulfilling marital conjugal duties. Similarly, a study by Callaway et al., (2015) based in Australia, looked at SHCs experienced by people with SCI within community living. The results showed that sexual difficulties impacted marital relationships. Despite the socioeconomic differences in these studies, the impact of sexual problems on relationships is significant. There is a strong need for sexual education and

sex therapy for couples to address their sexual health problems and openly discuss sexual health problems and find solutions together. Sexual health education can include positioning, management of SHCs, safe sex, and other forms of sexual pleasure and intimacy (Giurleo et al., 2022). More context-based studies on sexuality are needed.

Conclusion

Although sexual health is a human right and considered central to the quality of life, sexual health care for people with SCI are not prioritized. The study found that people with SCI are dissatisfied with sexuality and their long-term needs include the need for education around sexuality and sexual enhancement drugs. Therefore, understanding the experiences of people with SCI regarding sexual health will be useful in developing sexual programs that may be implemented to prevent the development of SHCs and thereby improve people's quality of life and mental health living with SCI. Emphasis on the importance of support for SHCs management should be central so that sexual activity is not affected.

Recommendations

Practice: Rehabilitation health professionals must not neglect to focus on sexual education and where to find helpful resources. Health education needs to also include SHCs and how to manage them.

Research: Topics on sexual diseases and reproductive health did not come up in the interviews. Future studies need to explore these topics. Future study on urban-based individuals with SCI is recommended at both government and private rehabilitation institutions.

Further research is required to determine the broader factors that influence sexual health problems and ways to improve the problem and meet their long-term care needs.

In this chapter the results as per the study objectives for sexual problems in SCI were presented. In chapter 5 the results for bowel and bladder problems in SCI will be presented

CHAPTER 5:

Bowel and bladder problems in people with spinal cord injury.

In this chapter the results for bowel and bladder problems will be presented. This chapter is written as a manuscript according to the journal guidelines. The study objectives were:

1. To explore the experience of bowel and bladder problems as well as sexual health in people with spinal cord injury (SCI).

2. To identify long-term care needs related to bowel and bladder problems in people with SCI.

Title	Bowel and bladder problems in people with spinal cord injury in Manguzi, KwaZulu Natal: Experience and long-term care needs
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Author contribution

	Lauren Tomes	**Sonti Pilusa**
Conceptualization	√	√
Method	√	√
Data analysis	√	√
Resources	√	
Manuscript writing draft	√	
Manuscript writing review and editing	√	√
Supervision		√

Title: Bowel and bladder problems in people with spinal cord injury in Manguzi, KwaZulu Natal: Experience and long-term needs

Background: The quality of life of people with spinal cord injury is significantly affected by secondary complications such as bowel and bladder problems. There is a need to explore the experiences of bowel and bladder problems among people with SCI in rural South Africa.

Objectives: This study explored the experiences of bowel and bladder problems and the long-term needs of people with spinal cord injury living in Manguzi, KwaZulu Natal.

Method: Twelve adults with SCI were recruited purposively. An explorative qualitative study design using semi-structured interviews was employed. The interviews were transcribed verbatim, and content analysis was conducted to identify the themes and categories.

Results: The themes that emerged from the experience of bladder and bowel problems were "no control" and "frustration". The categories related to the experiences were: types of bladder and bowel problems, managing bladder and bowel problems and the effects on well-being. The long-term care needs for bowel and bladder problems included access to proper toilets, nappies, medication (Dulcolax), ease of bowel movement, and health information on diet and how to manage their bowel and bladder problems better.

Conclusion: The findings show that bowel and bladder problems are frustrating people with SCI, and they affect well-being of people with SCI. Bowel and bladder management must be strengthened.

Keywords: spinal cord injury, bowel and bladder problems, long-term care needs.

Introduction:

The health and quality of life of people with spinal cord injury are severely affected by secondary health conditions (SHCs) (Pilusa et al., 2021 & Mashola et al., 2021). Bowel and bladder problems rank high among secondary health conditions that are unavoidable in people with SCI (Piatt et al., 2016). In South Africa, studies on SHCs in people with SCI are all based in urban settings (Pilusa et al., 2021; Madasa et al., 2020; Mashola & Mothabeng, 2019; Mashola, Olorunju & Mothabeng, 2019). There is a need for rural studies on SHCs.

The prevalence of bowel and bladder problems is high among people with SCI. Bowel problems have an estimated 60 -80% prevalence (Krassioukov et al., 2010; Pavese et al., 2019). A recent worldwide study by StrØm et al., (2022) reported a high prevalence of bowel problems (71%). Some factors associated with bowel problems include age, using laxatives/oral medications, level and severity of the lesion, abdominal pain, and access to healthcare (Tate et al., 2016). On the other hand, the prevalence of bladder problems ranges between 47 to 90% during the acute phase (Elmelund et al., 2018; Pelosi et al., 2021; Wahman et al., 2019) and post-discharge, it is 44-62% (StrØm et al., 2022; Madasa et al., 2020). Bladder problems are associated with complete SCI lesion, age, and gender, as females were more likely to have compromised renal functioning than their male counterparts in the long-term and this is likely because females were more likely to have a spastic bladder (Zhang and Liao, 2014; Elmelund et al., 2018).

The SCI injury causes significant sensory and autonomic problems causing either spastic or flaccid bowel or bladder (Anjum et al., 2020; Krassioukov et al., 2010). Flaccid and spastic bladder are the two types of bladder control problems, and depending on the nerves involved and the type of SCI the bladder can either be spastic bladder which means that it is overactive and retains urine or it is flaccid which means that it is underactive and is incontinent (Dorsher et al., 2012). Bowel problems often lead to severe, potentially life-threatening complications, such as constipation, autonomic dysreflexia, urinary tract infections (UTIs), sepsis, haemorrhoids, rectal bleeding, and prolapse (Pavese et al., 2019). These complications can further lead to potential haemorrhage on the brain (Pavese et al., 2019). The loss of bowel control, particularly bowel incontinence, is often described by those experiencing it as the most socially disabling aspect of their SCI, which can have a marked impact on a person's quality of life. Whilst the loss of bladder control causes incontinence, renal impairment, urinary tract infections and renal stones

(Taweel et al., 2015), bladder problems such as UTIs are ranked in the top three reasons for hospital readmission. This is due to the use of indwelling catheters instead of clean, intermittent self-catheterisation as well as a decline in neurological status, these contribute to disability and a decline in quality of life (Richardson et al., 2021, Mashola et al., 2019). Experiencing both bowel and bladder problems can severely affect the quality of life and have both medical and social consequences for persons living with a disability (Savic, Frankel, Jamous., et al., 2018; Pilusa et al., 2021; Fuseini et al., 2019).

Managing bowel and bladder problems is complex as there is no 'one size fits all approach' different people have different needs based on the severity, type and level of their SCI. It also depends on context, access to care and socioeconomic factors. People with SCI use different physical, pharmacological, and lifestyle techniques to achieve bowel continence and a successful bowel evacuation at the desired time (Abrams, 2017). For example, many people with SCI self-managed their SHCs by practising good hygiene which included the use of diapers, catheters, and over-the-counter medication (Pilusa et al., 2021) These may require modifications from time to time, or even a complete change, which is why bowel management issues form part of regular follow-ups after SCI (Abrams, 2017). On the other hand, the goal of bladder management is to maintain and preserve a functional and -free urinary system and maintain adequate bladder drainage (Sezer et al., 2015). The is no "gold standard" of bladder management; however, the aim is always to identify what best works for people with SCI and it could be a myriad of options, including timed voiding, education, intermittent catheterization, indwelling catheterization, pharmacological intervention, and even surgical management in severe cases (Sezer et al., 2015). Comprehensive bowel and bladder management that considers personal and environmental factors is crucial, because people with spinal cord injury experience challenges when preventing and managing SHCs. Some challenges include lack of access to healthcare, lack of health information, financial constraints preventing the purchase of necessary items to assist in managing their SHCs, indicating a need for regular follow-up care and regular evaluation of prevention strategies (Pilusa et al., 2021).

This study aims to explore the experience of bowel and bladder problems in people living with SCI to better understand their long-term care needs.

Methodology

Study Design

An exploratory qualitative approach using semi-structured interviews was used to help understand the experiences of bowel and bladder problems and identify long-term care needs related to bowel and bladder problems.

Study Setting

The study was based in a rural setting, Manguzi, KwaZulu Natal. With the assistance of Manguzi Hospital and its affiliation to Siletha Ithemba, a Non-Profit Organization (NPO) for people with disabilities from which we were able to recruit our participants. They (Siletha Ithemba) provide care for clients with disabilities. They provide psychosocial support, wheelchair skills, health education on secondary health complications, home visits, occupational and physiotherapy, and peer support.

Study Participants

The study included people with SCI known to Siletha Ithemba NPO in Manguzi, rural KwaZulu Natal. The inclusion criteria included people with a diagnosis of SCI despite the level of their lesion, the duration of their injury, or the severity of their lesion and they were required to be above 18 years of age. Purposive sampling was used to recruit participants.

Data Collection Tools

Semi-structured face-to-face interviews were used to obtain relevant data for qualitative analysis. The researcher developed an interview guide to facilitate these interviews. The interview guide consisted of two sections. Section A: Demographic data collection. Section B: Open-ended questions covered topics on bowel and bladder problems experiences, how they were managed and required long-term needs.

Data collection procedure

Data collection commenced after ethical clearance and permission to conduct research was received. A pilot study was conducted and then proceeded by the main study, where data collection was done using trained research assistants. The pilot study's purpose was to familiarise the researcher and research assistants (peer supporters) with the interview guide and to ensure efficiency and quality regarding the overall study procedure. No amendments were made to the interview guide or the study procedure. Each participant received a participant information sheet and provided written consent to perform the study as well as permission to audio record the interview, and suitable arrangements were made for the researcher and research assistant to visit the participants at their respective homes. The interviews were audio recorded and conducted in the language that the participants were comfortable in.

Data analysis

Microsoft Excel spreadsheet was used to capture demographic data. The audio-recorded interviews were transcribed verbatim (in Zulu) and then translated to English. All the transcripts were read and reread several times by the researcher. Two transcripts were coded manually by the two researchers and the findings were compared. A coding framework was developed and used to code the rest of the transcripts. Debriefing sessions were held to discuss and compare the findings.

Rigor

To ensure the trustworthiness of the data collected. Credibility was ensured by keeping a journal for reflection of not only the participants, but the researcher as well, to prompt: feelings, problems, ideas and assumptions regarding bladder, and bowel problems. To ensure accuracy of the interview interpretations, the interviews were all audio recorded so they could be replayed, and this helped with debriefing sessions between the researcher and research supervisor, which were all audio recorded so they could be replayed. This helped with debriefing sessions with the research supervisor who has experience in qualitative research design, ensuring all bases were

covered. To ensure dependability, an audit of the entire research process was kept, and a detailed description of the data collection, analysis and interpretation were outlined. All data was coded and stored on a password-protected laptop. For transferability, the participants' methodology and demographic data were explained in depth. To ensure confirmability, all interviews were audio recorded. An audit of the entire research process was also kept in the form of a written journal.

Reflexivity

Both researchers are physiotherapists with an avid interest in public health care, the approach has always been to understand the unmet needs of the community to provide better patient centred care. In order to do so, it is important to understand patients' experiences. Sexual, bowel and bladder problems is not an area that many physiotherapists focus on in depth even in a clinical space. But it is a need that SP identified that needs to be strengthened.

Ethical Clearance

Ethical approval from the Human Research Ethics Committee of the University of the Witwatersrand (M210813) and approval from the South African National Health Research Database (KZ_202201_018) were granted. Manguzi Hospital granted permission to use the study site for data collection. All the participants signed informed consent forms to participate in the study.

Results

We interviewed twelve people with SCI 83.33 (%) male and 91.67 (%) paraplegia. Table 1 below outlines the participants' demographic data. All the participants had bowel and bladder problems.

Table 5.1: Participants' demographic and injury profile

	N	%
Age Range, mean and SD	28-60 years, 43.83, 11.16	
Gender		
Female	2	16.67
Male	10	83.33
Marital status		
Single	10	83.33
Married	2	16.67
Qualifications		
Primary schooling	2	16.67
High school	5	41.67
Matric and Post matric	2	16.67
No schooling	3	25
Employment status		
Employed	2	16.67
Unemployed	10	83.33
Cause of injury		
Traumatic	8	66.67
Non traumatic	4	33.33
Type of injury		
Paraplegia	11	91.67
Tetraplegia	1	8.33
Completeness of injury		
Complete	3	25
Incomplete	9	75
Level of injury		
C1–C4	1	8.33
T7–T12	5	41.67

L1–L5	6	50
Date since injury Range, average, SD	3-33 years, 8.96 13.33	
Secondary health conditions		
Pain	11	91.67
Spasms	5	41.67
Pressure sores	5	41.67
Contractures	2	16.67

The themes that emerged from the experience of bladder and bowel problems were "no control" and "frustration."

The categories related to the experiences were:

1. Types of bladder and bowel problems.
2. Management of bladder and bowel problems.
3. Effects on wellbeing.
4. Long-term care needs.

The participants were all given pseudo names. They expressed the lack of control over bladder and bowel problems and the frustration broads these problems.

"I fail to control urine because when it pours esssh I cannot control it'. I don't know how I can explain it because I really don't have control over it" Peter, 30 years

"I experience challenges when it comes to urination." John, 28 years

1. Types of bladder and bowel problems

All the participants experienced bowel and bladder problems. The bladder problems experienced included incontinence, urinary tract infections, blood in urine and urinary retention. 100% had incontinence and all participants experienced UTI at some point in their journey with SCI.

1.1 Urinary incontinence

"It's like that, there is a time. I cannot control my urination but sometimes, I am able to control it. Like today, it was not very difficult but sometimes it gets difficult. At night I cannot lie. Urine just flows" Amy, 57 years

"At night essssh I have a problem. I can control urine while I'm still awake but once I fall asleep I wet my bed" Peter, 30 years

"There are times when the urine comes out fine because I use the catheter to draw urine. After drawing urine there is more urine that just pours." Sarah, 51 years

1.2 Urinary tract infections (UTIs)

"Sometimes I experience dark urine with bad smell even though I drink a lot of water, in that case I go to see a doctor" John, 28 years

"My urine is not clean, there is something that comes out of my urine. The dirt is like sperm or milk, usually experienced at the very end of urine. This dirt comes out even when I use the urinary catheter" Matthew, 51 years

"Just after removing the catheter I feel the heat" Sarah, 51 years

1.3 Blood in urine

"The blood on the urine has been coming out for a long time now." Junior, 46 years

1.4 Pain on the bladder and when urinating

"My bladder hurts a lot, I feel sharp pain and that make me visit the hospital regularly." Matthew, 51 years

"I experience pain on my bladder when urinating." Amy, 57 years

1.5 Urine retention

"Sometimes I get pressed with urine but urine does not want to come out or else it comes out slowly with no pressure" John, 28 years

"My urine comes in sessions as I experience breaks whenever urine is coming out and I can feel it that some of urine is left inside the bladder." Matthew, 51 years

"There are times when urine comes out fine, because I use the urinary catheter to draw urine. After drawing urine there is more urine that pours just after drawing it. Just after removing the catheter, I feel the heat and more urine flow" Samuel, 41 years

All the participants experienced bowel problems. All experienced incontinence at some point, 3 participants expressed diarrhoea was more frequent for them. The participant's experiences include incontinence, diarrhoea, constipation, and heartburn.

1.6 Incontinence

"I cannot control my poop, during defecation……. At this moment of our conversation, stool may just come out because I cannot control or hold it back." Matthew, 51 years

"I cannot feel it when I am pressed with stool. If I feel something it is a little feeling and I feel it very late by the time I have to poop immediately, by that time you cannot rush to the toilet." John, 28 years

1.7 Diarrhoea

"I struggle from diarrhoea that last for long time and when I have constipation it is hard for me to visit the toilet and take out stool, but I prefer constipation over diarrhoea or running stomach" Luke, 34 years

"I suffer from diarrhoea in most of the time, at the worse diarrhoea almost take all three weeks of the month leaving me with only one week relief to recover." Junior, 46 years

1.8 Constipation

My problem is that it takes me three days to visit the toilet for defecation. I have a problem of hard bowel movements which causes hard or stiff stool that are lump shaped" Matthew, 51 years

"Sometimes I experience hard stools constipation when I visit the toilet but sometimes my bowel get in good condition and I go to the toilet without any challenges." John, 28 years

"Sometimes I go to the toilet in a satisfactory way, but sometimes I spend the whole week without going to the toilet" Samuel, 41 years

1.9 Heartburn

"I get heartburn when I eat any kind of food. I feel like food does not get digested in a correct way and that leads to constipation or hard stool constipation." Matthew, 51 years

"I avoid eating things like spicy food and chillies, that is how I manage it." Luke, 34 years

"I think there is a problem with my digestive system because hard bowel movements causes discomfort inside my body and it results in heartburn, which is a bad feeling to me because it makes me feel like vomiting." Matthew, 51 years

2. Management for bladder and bowel problems

The participants managed bladder problems by using clean catheters, drinking water, practicing cleanliness, caregiver (table with quotes in appendix 1). While bowel problems were managed with a stoma bag, gloving, diet, nappies, medication, positioning, and heat therapy to manage bowel problems. Quotes illustrated in appendix 1

Figure 5.1: Bowel and bladder management strategies

3. Effects of bowel and bladder problems on well-being

The participants explained how bowel and bladder problems affected mental health, social lives, time, and finances.

3.1 Mental impact

The participants expressed feelings of sadness, frustration, fear, embarrassment, and worry related to bowel and bladder problems. For example, John, 28 years reported that *"The bladder problem is very frustrating because I wake up at night being pressed with urine but end up fighting with my bladder for a very long time for it to release urine."*

Junior, 46 years felt fear of leaking "*When I'm around people I stay in fear that urine might just flow."*

Some participants worried and stressed about bowel problems:

"My body tells me when it is time to visit the toilet, but the stiffness of my stool worries me." Tom, 38 years

"My heart beats faster if I spend a long time without going to the toilet for defecation, then I feel stressed and frustrated and end up losing hope in life." Samuel, 41 years

3.2 Time

Managing bladder and bowel problems took time. The participants said they had to wait for long for urine and stools to come.

"I must wait until the stool comes, you can wait up to an hour and relax up until the stool comes out." Junior, 46 years

"I wait for five minutes for urine to come out, but that time I will be on rush or in need to go somewhere." John, 28 years

"I can feel urine coming but still have to wait for a long time for urine to come out" Tom, 38 years

"When I visit the toilet, I am forced to wait for a long time before defecation process because of hard stools constipation." Tom, 38 years

3.3 Social lives

The presence of bladder and bowel problems affected the participants' social lives. The participants avoided being with people due to fear of leaking:

"When I'm around people I stay in fear that urine might just flow." Junior, 46 years

"Ahhh the problem of urine bothers me the most when I am around people. Sometimes, I isolate myself from people because I might wet my pants on their presence." Harry, 51 years

Urinary and bowel incontinence affected the participants' trips especially when using public transport.

"The flow of urine while you are trying to get into a car, then your trip just gets interrupted. You will wet your pants. This thing affects my life because my trip gets distracted." Junior, 46 years

"If I don't use a catheter I wet myself at the time where I must get into a public transport." Samuel, 41 years

"My bowel condition restricts me from using public transport because most drivers often assume that a person on the wheelchair might poop in their cars because of their disability" Tom, 38 years

3.4 Bowel and bladder problems affected intimate relationships.

"Bowel problems affect me the most because I have a wife, when we cannot help each other and do our things (sex) so yaaaah…. It can't happen. So yaaaah that where it affects me the most." Samuel, 41 years

3.5 Causes other secondary complications.

The participants pointed out that some catheters caused discomfort and pain as expressed by participant 1 *"Another thing is that the urinary catheter pipe hurts me inside when I insert it. Other pipes are soft they do not hurt me, I prefer soft and easy pipes because they bend easily. Some pipes are very sharp they cut me when I insert them."* Matthew, 51 years

"Hard stool constipation gives me hard times because my anus hurts during defecation as it swells and expands from internal pressure." Tom, 38 years

"I feel severe pain in the process of changing the urinary catheter. When the blockage takes place, I experience severe head ache which I can't stand" Chris, 40 years

"Mmmmh yaaaaah… it really affecting me. Your body loses energy if you have challenges of going to the toilet. I experience discomfort." Harry, 51 years

Some catheters caused infections.

"The thing of catheterizing can cause infections to other people. I decided to use the condom catheter even though it also causes internal infection because I cannot draw all the urine." Samuel, 41 years

"The problem about diapers is that they are hot and your buttocks get hard-pressed. The heat causes pressure sores, that why I avoid wearing diapers." Samuel, 41 years

"Nappies are hot which makes my wounds delay to heal, that how I struggle" Luke, 34 years

"The problem is that Dulcolax is expensive for me and that means I must have money in order to afford it, which is why I use traditional medicine for constipation relief." John, 28 years

4. Long-term care needs

The long-term care needs related to bowel and bladder problems included information, medication, and quality catheters. The participants needed information on how to manage bowel and bladder problems. Some participants needed medications (Dulcolax) to relieve constipation, proper toilet facilities, and access to quality catheters. The table below outlines the long-term needs for bowel and bladder problems.

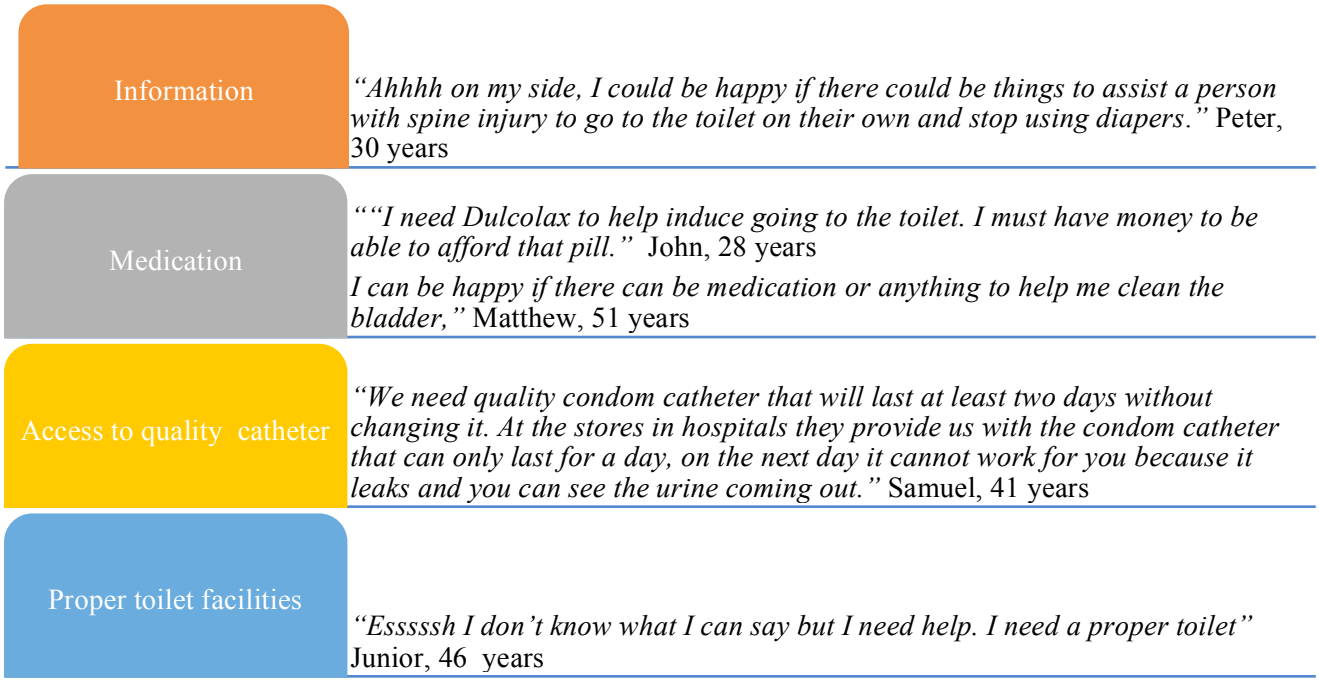

Figure 5.2: Long-term care needs for bowel and bladder problems.

Discussion:

This study aimed to identify the experience of bowel and bladder problems in people living with SCI as well as to help identify their long-term care needs. The main themes that emerged for bowel and bladder problems were *"frustration"* and *"no control"* respectively. The participants were frustrated at how their bowel and bladder problems have taken over their daily lives and because of no control of their bladder or bowel functions. A sense of frustration and no control is common among people living with SCI (Callaway et al., 2015; Fuseini et al., 2019). A study by Pilusa et al., (2021) looked at SHCs and their impact on people with SCI and reported that the presence of SHCs impacted the participants' psychological, physical, and social wellbeing. This also prevented them from engaging in marital obligations as they reported that emptying of the bowel and bladder takes time. These findings are similar to previous studies on people with SCI (Pilusa et al., 2021; Fuseini et al., 2019).

The participants expressed how bowel and bladder affected their mental health and social lives. Similar to studies by Pilusa et al., (2021) and Fuseini et al., (2019) the participants expressed worry and fear of leaking in social spaces. The fear of being in social spaces can promote

isolation, which can cause depression (Wheeler et al., 2018). Bowel and bladder problems also affected intimacy as participants expressed that emptying their bowel and bladder before intimate acts took time or that their partners did not understand them. A qualitative study by Braaf, Lennox, Nunn and Gabbe, (2017) conducted in Australia reported how bladder and bowel problems alter intimate relationships and can strain family and friend relationships. There is a need to ensure adequate bowel and bladder management practice to the daily lives of SCI patients and support for patients struggling with bowel and bladder management.

Management of SHCs, such as bowel and bladder problems are not easy (Pilusa et al., 2021). The study participants managed bowel problems with a stoma bag, gloving, diet, medication, nappies, positioning, and heat therapy. These methods are echoed in SCI care guidelines (Kurze et al., 2022). However, the management methods should, therefore, always consider the individual situation of the person concerned, and the correct application is always a prerequisite for success. Essentially bowel management has many facets to it; therefore, education on various management methods is essential. A study by Savic et al., (2018), indicates that people with long-term SCI, require a change in their bladder and/or bowel management methods at some point for either medical or practical reasons, which proves that a simple to-do checklist is not adequate. This indicates a constant need for education on management strategies. Bladder problems were managed with nappies, medication for UTIs, catheterisation, drinking water, and applying pressure on the bladder. It is interesting to note that normal/reflex voiding is a seemingly more common practice for bladder problems in people with SCI in developing countries (Chen et al., 2016), possibly due to the cost implications associated with catheterization. It is important that we emphasize good bladder health to avoid hospitalisation. Secondary health conditions can disrupt one's life.

The financial and health impact of managing bowel and bladder must not be underestimated. It was interesting to see how most participants used nappies either when travelling or at night to avoid leaking. Given the cost of nappies and the fact that most of the participants were unemployed and depending on a social grant, this impacted them financially. Other methods used were gloving or wearing no underwear when at home as toilets were easily accessible. For bladder management, most participants used catheters and complained that the quality of the catheters were not great and that they were not readily accessible at clinics and hospitals. Living

with a disability can be financially costly due to disability-related costs such as day to day support and access to care (Hanass-Hancock et al., 2017). Secondly, the use of medication for pain, Dulcolax for constipation and antibiotics for UTIs, must be monitored because people with SCI are at high risk for polypharmacy (Patel et al., 2017). Understanding long-term care needs can inform planning and resource allocation to meet the needs of people with SCI. The long-term needs related to bowel and bladder problems included health information, access to medication, proper toilets, and quality catheters. The participants needed health information on how to manage bowel and bladder problems. Empowering people with information on SHCs and management strategies is core to person-centred care and needs to be done continually to meet the needs of people with SCI (Pilusa et al., 2021). Community-based interventions such as the one conducted by Hossain et al. 2020 can help increase health literacy. However, social challenges such as poverty and access to basic resources such as clean water and sanitation are also important to ensure better health (Hossain et al., 2020; Pilusa et al., 2022). Factors such as age, educational status, the severity of the SCI, and patient motivation must also be considered when conducting health education (Evardone et al., 2018).

The second long-term need was access to medication and quality catheters. In order to better manage SHCs, people with SCI need access to appropriate medication and assistive devices (Pilusa et al., 2022). Medication for SHCs such as pain, UTI and severe constipation, healthcare facilities sometimes experience medicine stock outs and shortages (Ndzamela et al., 2020) or a lack of medication specifically for people with SCI (Pilusa et al., 2022). Medication and catheters must be readily available in primary and district healthcare facilities to avoid out-of-pocket expenses and economic vulnerability, given that most people with disability are unemployed (Hanass-Hancock et al., 2017). Care programs and health planning for persons with disabilities must adopt long-term perspectives to ensure access to essential services, assistive devices, and medicine without worsening the individual financial status.

Conclusion

The findings show that bowel and bladder problems are frustrating people with SCI, and they affect the well-being of people with SCI. These findings point to the need for health professionals and policymakers to strengthen bowel and bladder care for people with SCI. This

study looked at the aspects of bowel and bladder management that people living with SCI found most challenging and how it affected their QoL and mental health. The information gained will help develop more effective bowel and bladder programs that may be implemented to prevent the development of SHCs (including pain) and as a result, improve the QoL and mental health of people living with SCI.

There is a need to strengthen prevention care for SHCs throughout the lifespan of people living with SCI is crucial. This study confirms the importance of assessing the effectiveness of health intervention and the need for a holistic prevention model of care whereby rehabilitation health professionals must focus on minimizing the development of SHCs and introducing social education to increase support from friends, family, and society at large. This should include aspects that provide specific education on good bowel and bladder practice for people with SCI, how to promote a healthy lifestyle, to offer a sense of support, self-management strategies, and continuity of care. There remains an urgent need to identify sustainable ways to reduce the prevalence of SHCs after discharge from hospitals with SCI in low- and middle-income countries.

Recommendations

Policy: Health planning for the needs of people with SCI is needed to ensure access to medication and quality catheters

Research: Further research is required to determine ways to strengthen bowel and bladder care for people with SCI and improve the problem and meet their long-term care needs.

Practice: Bowel and bladder education should ideally be part of rehabilitation for people with SCI and research on therapeutic interventions for best-practice care in people living with SCI is highly recommended.

In this chapter the results as per the study objectives for bowel and bladder problems in SCI were presented. In chapter 6 the results for health intervention in SCI will be presented

CHAPTER 6

Health intervention program for people with spinal cord injury.

In this chapter, the results for the health intervention program will be presented. This chapter is written as a manuscript according to the journal guidelines. The study objectives were:

1. To determine the effectiveness of the health intervention program for bowel, bladder, and sexual problems on quality of life (QoL).

2. To determine the effectiveness of the health intervention program for bowel, bladder, and sexual problems on mental health in people with SCI.

Title	**Health intervention for people with spinal cord injury addressing bowel, bladder, and sexual problems in KwaZulu Natal, South Africa.**
Journal	**Malawi Medical Journal**
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Author contribution

	Lauren Tomes	**Sonti Pilusa**
Conceptualization	√	√
Method	√	√
Data analysis	√	√
Resources	√	
Manuscript writing draft	√	
Manuscript writing review and editing	√	√
Supervision		√

Title: Health intervention for people with spinal cord injury addressing bowel, bladder, and sexual problems in KwaZulu Natal, South Africa.

Abstract

Background: Living with a spinal cord injury (SCI) and developing secondary health conditions that develop due to the primary disability can affect the quality of life. Studies on health interventions in people with SCI are scarce in South Africa.

Objectives: To determine the effectiveness of the health program on the quality of life (QoL) and mental health of people with SCI

Method: A Quasi-Experimental quantitative design was used. A face-to-face health program on the prevention and management of bowel, bladder, and sexual problems in SCI was conducted for the participants with SCI. WHOQoL-Bref and SF-12 questionnaires were administered before and six weeks post-intervention respectively. Paired t-test was used to identify changes in QoL and mental health pre and post-intervention. Significance was set at p-value ≤ 0.05.

Results: Nineteen participants were recruited, the majority (74%) were male and had traumatic SCI (84%)**.** There were no statistically significant changes in the pre-test and post-test scores of both the quality of life and mental health.

Conclusion: The findings show that a health program focusing only on health education alone will not affect mental health and quality of life in people with SCI. Other factors influencing the quality of life and mental health of the people with SCI such as the presence of secondary health conditions, social support, access to health care services and unemployment should also be considered when developing future interventions.

Keywords: Spinal cord injury, mental health, quality of life, secondary complications

Introduction:

People with spinal cord injury (SCI) experience other health conditions that are highly disruptive and require a considerable coping process (Berwick et al., 1991; Strøm et al., 2022). These conditions are called secondary health conditions (SHCs) and they include pain, pressure sores, contractures, depression, sexual problems, bowel, and bladder problems to name a few Strøm (et al., 2022; Pilusa et al., 2021). These conditions affect general health, quality of life (QoL) and mental health (Mashola et al., 2019).

Improving QoL is the ultimate goal for chronic and disability care management. Quality of life (QoL) is "defined as an individual's perception of their position in life within a specific context in relation to their goals, expectations, standards, and concerns" (WHO, 1996). Quality of life domains includes physical, psychological, social, and environmental health. QoL in people with SCI is significantly associated with SHCs, decreased social interaction, decreased mobility, overall health behaviour and environmental accessibility (Mashola et al., 2019; Halvorsen et al., 2021) When planning for SCI care, QoL outcomes must be incorporated and planned for in treatment intervention.

Spinal cord injury is physical injury, as such the mental health component of an individual with SCI tends to be neglected. Mental health is defined as "a state of mental well-being that enables people to cope with the stresses of life, realize their abilities, learn well and work well, and contribute to their community" (WHO, 2023). People with SCI experience mental health challenges including anxiety, depression and post-traumatic disorder (Khazaeipour et al., 2015; Schultz et al., 2022). The emotional and cognitive impact of SCI on an individual varies over time and can be influenced by cultural and contextual factors. In addition, the presence of other SHCs affects mental health. For example, SHCs such as pain and sexual problems can cause a lot of stress and worry in people with SCI (Pilusa et al., 2021). Therefore, rehabilitation for people with SCI must be holistic to ensure that physical and mental well-being are strengthened.

As suggested in a study by Pilusa et al., (2022) a model of care for people with SCI needs to be patient centred. The main focus for patient centred is ensuring that the patients is empowered and involved in the whole care. Pilusa et al (2022) identified services that are critical in preventing SHCs. Some of the services include health education programmes, access to rehabilitation services, and needed assistive devices. This health interventions have not been researched in

South Africa. Thus, the objective of this study was to determine the effectiveness of the health education program on the quality of life (QoL) and mental health of people with SCI.

Methodology

Study Design

Quasi-experimental pretest post-test design where the dependent variable was measured before and after intervention with an independent variable (Stratton, 2019).

Study Setting

This study was conducted in a rural setting in the region of Manguzi, in KwaZulu Natal, South Africa. It was conducted with assistance from Manguzi Hospital and its association with Siletha Ithemba, a Non-Profit Organisation (NPO) for people with disabilities where we were able to recruit our participants for this study. Siletha Ithemba NPO provides inclusive and holistic community-based care for clients with disabilities, and these include psychosocial support, wheelchair skills, health education on secondary health conditions, home-based care and peer support.

Study Participants

The study included purposively recruited community-dwelling people in Manguzi, KZN with SCI who are served by the Siletha Ithemba NPO. Only people with SCI, who met the inclusion criteria and who were above the age of 18 were included in the study. From the previous chapters the twelve participants were all included in this purposive sampling as well. In total there were nineteen participants.

Data Collection Tools

The data collection tool had three sections. Section A: included demographic data: age, gender, level, and severity of SCI, employment status, level of education, marital status, transport, dependents, caregiver and secondary health conditions. Section B: included questions on QoL using the WHOQoL-Bref questionnaire. Section C: included questions on physical well-being and mental health using the SF-12 questionnaire.

The WHOQoL-BREF was used to measure the quality of life before and six weeks after the health program (WHO, 1996). The WHOQOL-BREF has 26 questions addressing physical health (7 items), psychological health (6 items), social relationships (3 items), environmental health (8 items) and general health items. The scoring is from 1 to 5 per item/question. The scores are then transformed linearly to a 0–100 scale. The higher the score the better the perceived QoL. The WHOQoL-BREF showed high reliability with Cronbach's $\propto$ = 0.74–0.87 and it has been used in people with SCI in South Africa (Mashola et al., 2019).

The Short form-12 (SF-12) questionnaire was used to assess mental health (Whitehurst et al., 2014). SF-12 has two domains: physical component summary (PCS) and mental component summary (MCS). The SF-12 assesses the impact of health on an individual's everyday life. Scores range from 0 to 100, with higher scores indicating better physical and mental health functions. The SF-12 has good sensitivity and specificity relative to other screening tools for depression and other mental disorders (Berwick et al., 1991).

Data Collection Procedure

A pilot study was conducted before the main study in previous chapters. Questionnaires were administered telephonically in a language understood by the participants (IsiZulu) a week before the health program and again six weeks after the health program by the trained research assistant. All the participants were invited to the hospital where the health education programme (Appendix 9) used as a guide occurred. The patients came to the hospital for a consultation with a rehabilitation doctor for an assessment of general health including a bowel and bladder check-up. The assessment included: a kidney ultrasound, blood pressure, and a review of current bowel and bladder management. After the consultation, a group health education session was conducted by the health professionals on bowel, bladder and sexual problems and prevention and management practices.

Data analysis

Demographic data as well as data from the questionnaires were captured on a Microsoft Excel spreadsheet. Descriptive and inferential statistics, using StataSE version 17.0 were conducted. Demographic data were analyzed using percentages, means and standard deviations. Data were

analyzed using medians to determine interquartile ranges (IQR) for WHOQoL-BREF and SF 12 data. Association between pre-test and post-test scores were analyzed using the paired t-test. Significance was set at p-value ≤ 0.05.

Ethical Clearance

Ethical clearance was granted by the University of the Witwatersrand's Human Research Ethics Committee (clearance certificate number: M210813). This research study is registered with the National Health Research Database (KZ_202201_018). Permission to conduct the study in KZN at Manguzi Hospital was also granted. The purpose of the study was explained to individuals with SCI. Informed consent was sought from all the individuals with SCI.

Results

Nineteen people with SCI were included in the study, 73.68% male with a mean age of 45 years. The majority of the participants had paraplegia and incomplete lesion. Table 6.1 presents the participants' demographic details and Table 6.2 presents the injury profile.

Table 6.1 Participants' demographic

	N	**%**
Age Range, mean and SD	28 – 60 years, 45.28, 9.57	
Gender Female Male	5 14	26.32 73.68
Marital status Single	14	73.68

Married	5	26.32
Qualifications		
Primary schooling	3	15.79
High school	5	26.32
Matric and Post matric	3	15.79
No schooling	8	42.11
Employment status		
Employed	3	15.79
Unemployed	16	84.21

Table 6.2: Participants' SCI profile

	N	**%**
Cause of injury		
Traumatic	16	84.21
Non traumatic	3	15.79
Type of injury		
Paraplegia	18	94.74
Tetraplegia	1	5.26
Completeness of injury		
Complete	6	31.58
Incomplete	13	68.42
Level of injury		
C1–C4	1	5.26
T7–T12	10	52.63
L1–L5	8	42.11

Date since injury Range, average, SD	3 – 33 years, 8.18, 15.55	
Secondary health conditions		
Pain	16	84.21
Spasms	6	31.58
Pressure sores	5	26.32
Contractures	6	31.58
Bowel problems	4	21.05
Bladder problems	5	26.32
Sexual problems	16	84.21

WHOQoL- Bref Results

The baseline total mean score for QoL was 74.83 SD 13.59. The highest mean score was for psychological health and environmental health. Table 3 below illustrates the baseline scores for all the QoL domains.

Table 6.3 Baseline scores for all the QoL domains

	Domain 1 Physical Health	**Domain 2 Psychosocial Health**	**Domain 3 Social Relationships**	**Domain 4 Environmental Health**
P50	20	22	9	22
P25	18	21	8	18
P75	23	25	10	24
Mean	20.89	22.68	9.21	22.05
SD	4.82	2.75	2.35	3.67

There was no major increase between QoL before and after the intervention. At P75, there was a slight increase in the means scores for physical health, psychosocial health, environmental health

and social relationships domains. In all the domains there was a slight increase in the mean scores.

Table 6.4 QOL domains before and after the intervention

	Domain 1 Physical Health		**Domain 2 Psychosocial Health**		**Domain 3 Social Relationships**		**Domain 4 Environmental Health**	
	Before	After	Before	After	Before	After	Before	After
P50	20	21	22	23	9	9	22	23
P25	18	18	21	21	8	8	18	19
P75	23	23	25	24	10	11	24	27
Mean	**20.89**	**21.11**	**22.68**	**22.79**	**9.21**	**9.42**	**22.05**	**23.11**
SD	4.82	4.77	2.75	2.94	2.35	2.32	3.67	4.29

There was no statistical difference between before and after the interventions as illustrated in table 6.3 and table 6.4.

Table 6.5: Paired t-test WHOQoL-Bref raw scores

	Before (mean)	**After (mean)**	**Paired Test**	**P-Value**
Physical Health	20.89	21.11	-0.3660	0.7186
Psychosocial Health	22.68	22.79	-0.2705	0.7899
Social Relationships	9.21	9.42	-0.3797	0.7086
Environmental Health	22.05	23.11	-1.1413	0.2687
WHOQoL Total	74.84	76.42	-1.0985	0.8568

SF 12 scores

The mean baseline score for the mental health scores was 19.37 and for physical scores 17.37. Table 6 presents the MCS and PCS scores

Table 6.6 Baseline scores for SF 12

	MCS-12	**PCS-12**	**Total SF-12**
	Baseline	Baseline	Baseline
50th percentile	19	17	36
25th percentile	18	15	34
75th percentile	22	19	41
Mean	19.37	17.37	36.74
SD	2.56	3.96	3.60

There were no differences in scores before and after intervention for the MCS before and after the intervention illustrated in figure 1. PCS showed a very slight improvement of 0.03 in SD, which is not statistically significant. Total SF-12 however showed an improvement of 1.76 in SD which is also not statistically significant but indicative of some change.

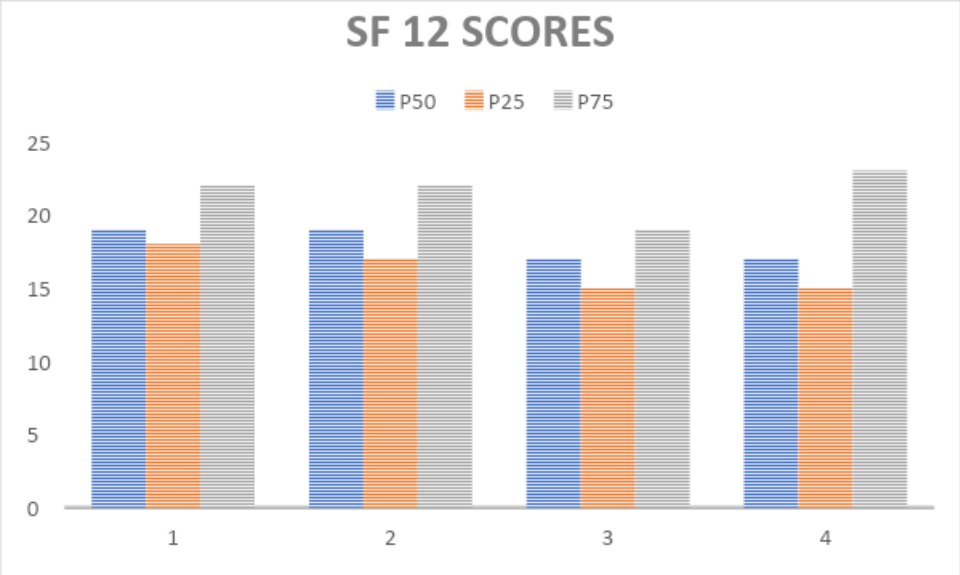


Figure 6.1: Interquartile ranges P50, P25 and P75 for PCS and MCS before and after the intervention.

There was no statistical significance in the pre and post-intervention results for SF-12 as illustrated in table 7.

Table 6.7: SF-12 scores difference between before and after the intervention

	Before (Mean)	**After (Mean)**	**Paired T-test**	**P-Value**
PCS	17.36842	17.42105	-0.0885	0.9305
MCS	19.36842	19.73684	-0.5159	0.6122
Total SF-12	36.73684	36.63158	0.1325	0.8960

Discussion

This study aimed to identify the effectiveness of a health education program on the quality of life and mental health of people with SCI. To our knowledge, this is the first intervention study focusing on people with SCI in rural South Africa.

Living with a disability such as SCI can negatively affect health and QoL. In our study, the total baseline mean QoL score was 74.83 indicative of a very good QoL. In comparison with a South

African-based study by Mashola et al., (2019), on the associations between health behaviour, secondary health conditions and quality of life in people with spinal cord injury the QoL scores in our study was higher. The study by Mashola et al., (2019) found a mean of 64.78. The difference in scores could be linked to the fact that the study by Mashola et al., (2019), recruited participants at a private hospital in an urban setting and the study participants had more severe injuries (complete lesions). We found the lowest score was in the social relationships domain. Social relationships play a vital role in an individual with a disability. Social support is important when managing secondary health conditions such as bowel and bladder problems, assisting with daily self-management practice and offering support to the individual with SCI (Guilcher et al., 2012; Munce et al., 2014). As such it is important to empower the caregiver or family member on SCI, and how to give support to minimise caregiver strain.

Although QoL was already high before the intervention, there was no significant difference between pre and post-intervention scores (p-value > 0.05). Possible reasons for no change in scores could be due to the existing presence of multiple SHCs such as pain, sexual problems, and bowel and bladder problems. The presence of these SHCs such as pain can affect physical and emotional well-being (Pilusa et al., 2021; Mashola et al., 2019). Secondly, other influencing factors, albeit not direct, include the lack of social support and unemployment, which could have contributed to the lack of change in QoL (Geyh et al., 2013). The majority of the study participants were unemployed and single and still reported a high QoL, hence employment although receiving a grant, and social support may not be direct contributing factors to QoL in people with SCI. Lastly, the intervention was a once-off health education; retention of health knowledge may be affected by the timing of the health information, age, marital status, educational status and gender (Tederko et al., 2017). The majority of the study participants had no schooling. Although the health information was conducted in the language that all the participants could understand (IsiZulu), repeating the information and simplifying the information could have been beneficial. Future studies can explore information needs and ways people with SCI want to be educated.

The baseline mean SF-12 scores were lower indicative of both physical condition and clinical depression. Poor mental health in people with SCI is not surprising and it is common (Khazaeipour et al., 2015; Lim et al., 2017). People with SCI experience depression and anxiety

throughout the disability journey. Poor mental health can be influenced by the severity of the disability, strained financial status and the presence of social support (Khazaeipour et al., 2015; Zürcher et al., 2019). Also, the presence of secondary health conditions tends to worsen the disability status and affects mental health negatively (Pilusa et al., 2021; Mashola et al., 2019; Richardson et al., 2021). In our study the participants experienced secondary health conditions such as pain, sexual health problems, spasms, bowel and bladder problems. When managing individuals with SCI the mental health components must also be addressed.

Mental health scores increased slightly after the interventions, albeit the change was not significant (p-value>0.05). Although mental problems fall under SHCs, the presence of other SHCs such as pain, bowel and bladder problems and sexual health problems can also cause anxiety, stress and worry among people with SCI (Pilusa et al., 2021; Callaway et al., 2015). Secondly, the fact that the physical scores were also low could also mean that the perceived severity of the disability has an impact on the mental health domain. This highlights the need for long-term support for people with SCI to live well with their disability. Peer support could help minimize the impact on mental health, by creating a space where specific SCI issues can be discussed and learn from each other (Joseph et al., 2016).

There is a need to ensure a systems perspective when developing interventions for people with SCI. The focus of the intervention was health education. Given the fact that there are multiple factors affecting people with SCI and their well-being, it would have been better to incorporate other strategies to support the interventions such as telehealth (sending reminders via WhatsApp), home visits and peer support. A good example of a multifaceted intervention is from a study by Chishtie et al., 2019. The intervention included health education, home visits and peer support, specific to the patient's needs regarding pressure sore prevention. The intervention was effective as the majority of the participants did not develop pressure sores (Chishtie et al., 2019).

Conclusion:

The findings show that a health education program on bowel, bladder and sexual problems did not have an overall effect on QoL and mental health in people with SCI. Future studies can develop intervention studies that can support people with SCI throughout the continuum of care.

The intervention can include health information on SCI and SHCs, peer support and access to home visits.

Limitations of the study:

The results were expected as realistically speaking six weeks is a very short time to assess the effectiveness of an intervention program in people with SCI as multiple factors impact their mental health and QoL. That said, six weeks may be enough to prevent further complications of SHCs mentioned in previous chapters and such an example is preventing incorrect catheterisation. The findings cannot be generalized because a small population was used for this study. Most of the participants were primarily men, paraplegic and had traumatic spinal cord injuries. Although this represents the general SCI prevalence, a diversity of SCI profile would have made for a more diverse response from participants. The study was also conducted in rural South Africa, findings in urban areas may differ as social circumstances may be different. Selection bias may have occurred as Siletha Ithemba NPO assisted in the selection of the participants who were easily accessible.

In this chapter the results as per the study objectives for the effectiveness of the health program for bowel, bladder, and sexual problems on quality of life (QoL) and mental health.in SCI were presented. In chapter 7 all the objectives of the entire study will be discussed.

CHAPTER 7

DISCUSSION

In this chapter, the findings of the study will be briefly discussed in accordance with the study aim and objectives. The study aimed to explore the experience of bowel, bladder and sexual problems and the effectiveness of a health intervention program on the quality of life and mental health in people with SCI in the rural region Manguzi in KwaZulu Natal, South Africa. The study objectives were:

1. To explore experience of bowel, bladder, sexual problems as well as sexual health in people with spinal cord injury (SCI).
2. To identify long-term care needs related to bowel, bladder, and sexual problems in people with SCI.
3. To determine the effectiveness of the health program for bowel, bladder, and sexual problems on quality of life (QoL).
4. To determine the effectiveness of the health program for bowel, bladder, and sexual problems on mental health in people with SCI.

Secondary health conditions such as bowel and bladder problems and sexual problems are rated as unavoidable in people with SCI. In addition, these SHCs tend to co-occur (Park et al., 2017). In this study, all the participants experienced bowel, bladder, and sexual problems. The types of bowel problems experienced included constipation, diarrhoea, and rectal bleeding. The types of bladder problems include incontinence, renal impairment, and urinary tract infections and this is similar to what has been reported in other studies (Pavese et al., 2019; Taweel et al., 2015). Sexual problems experienced by the study participants included decreased libido, erectile problems, ejaculatory problems, pain during sex, and anorgasmia amongst males; and altered sexual desire and arousal, altered genital sensation, altered vaginal lubrication, altered vaginal accommodation, satisfaction, pain, and orgasm amongst women (Aikman et al., 2018; Giannopapas et al., 2021). For sexual problems what was surprising is the fact that women were nonchalant about discussing sexual-related problems because they had either blocked that part of their lives out and felt like they were no longer desirable to men as they were older now or

according to the other female participant has just not had sex. The fact that these SHCs co-occur proves that there is a great need to understand how people with SCI experience them.

The experience of SHCs tends to revolve around personal wellbeing. The study participants expressed how frustrating the bowel, bladder problems were and felt that they lacked control. In addition, similar to previous studies bowel and bladder problems affected relationships, social participation, physical and mental wellbeing (Pilusa et al., 2021; Fuseini et al., 2019). On the other hand, the main theme that emerged for sexual problems was "dissatisfaction". The participants were not satisfied with their sexual lives because they reported that they were unable to maintain an erection and were therefore worried that their partners would leave them as a result. They also reported that emptying the bowel and bladder before sexual activity took an increased amount of time. There was an overall feeling of failure to perform as well as an altered perception of self. These findings are also echoed in various studies (Callaway et al., 2015; Pilusa et al., 2021; Fuseini et al., 2019). Care for people with SCI must seek to minimize such experiences related to SHCs.

Prevention and management of SHCs is not easy for people with SCI (Pilusa et al., 2021). The participants in this study managed their bladder problems with nappies, medication for UTIs, catheterisation, drinking water, and applying pressure on the bladder. These methods are echoed in SCI care guidelines (Kurze et al., 2022; Chen et al., 2016; Pilusa et al., 2021). Living with a disability is extremely costly and the financial impact of managing SHCs should therefore not be underestimated either (Hanass-Hancock et al., 2017). The participants in this study used nappies when they travel to manage bowel and bladder problems. This could mean that they do not have alternative options for managing their bowel and bladder problems. The other worry or concern about using nappies is the cost of nappies and the risk of developing pressure sores. Therefore, education on various management methods is essential as well as always considering the individual situation of the person concerned. Apart from that, correct application is also always a prerequisite for successful management strategies (Savic et al., 2018).

The management of sexual problems is usually neglected (Courtois et al., 2015). In this study, sexual problems were managed with medication (sexual enhancement pills as well as pills for pain), managing their SHCs such as emptying bowel and bladder before acts of sexual intercourse, position and diet or simply ignoring one's sexual feelings. Although the participants

had multiple strategies to manage sexual problems, managing sexual problems was a struggle. This is similar to the findings by Pilusa et al., (2021). It was interesting to hear that using cheese can be used to enhance sexual performance. Studies on diet and sexual problems have reported that a healthy diet may play a role in lowering erectile dysfunction in men (Bauer et al., 2020). Sex education should ideally be a part of holistic rehabilitation care, still taking into account cultural and religious views of people with SCI. Interventions to address sexual problems could include important conversations around sexual health, sexual engagement, reproductive health, and safe sex, health diet as well as where to access medication that can help people with SCI manage sexual health problems (Pilusa et al., 2022; Giurleo et al., 2022). These are conversations which healthcare professionals tend to shy away from.

Spinal cord injury is a chronic condition, which needs long-term continuity of care. The participants' long-term care needs related to bowel and bladder problems included health information, access to medication to treat urinary tract infections, proper toilets, and quality catheters. Participants expressed the need for information on how to best manage their SHCs. The long-term needs related to sexual problems included information and medication. The participants needed information on how to better manage SHCs such as pain that impact sexual experience, education on sexuality including sexual health, safe sex practices and positioning (Pilusa et al., 2021; Giurleo et al., 2022). Studies by Evardone et al., (2018) and Pilusa et al., (2021) have also highlighted the need for health information on SHCs. One of the key elements in managing chronic conditions is empowering patients with information on their conditions, and how to self –manage. Other services needed to better manage SHCs include access to adequate healthcare, continual rehabilitation care and health promotion services (Pilusa et al., 2022). Research on the package of care for people with SCI is needed. We already have a better understanding of their needs from the previous chapters, thus tailoring a health intervention programme catering to their needs provides holistic and patient centered care.

Secondary health conditions can affect quality of life and mental health negatively. A study by Adriaansen et al. (2016), looked at the prevalence of SHCs in people living with SCI for at least ten years and the correlation between SHCs and their QoL. The authors found that although SHCs such as musculoskeletal pain, pressure sores, spasticity, and constipation were common attributes in long term SCI, they lowered the QoL (Adriaansen et al. 2016). The baseline QoL

was high. The domain that had the lowest score was for social relationships. This could be due to financial strain, therefore lack of money to pay a caregiver or stigma around disability. The majority of participants were single. With regards to mental health the mental health domain was low indicating the presence of possible depression, as we are unable to make a diagnosis and would need to refer to psychology. The mean scores were even lower than the reported mental health scores for people with SCI in Bangladesh (33.9 using SF12) in a study by Hossain et al., (2020). Possible reasons for the low score in our study could be the presence of SHCs that can cause stress and worry (Pilusa et al., 2021) and these sentiments were echoed in previous chapters. Mental health is closely linked to physical health. The physical score was also low indicating the severity of the disability. When rehabilitating people with SCI collaborative care is important to ensure that both physical and mental health is addressed.

Multifaceted community-based interventions are needed to support SCI care. Our study used health information of SHCs and health checks to increase QoL and mental health. There was no significant change in QoL and mental health post intervention. Possible reasons could be that QoL can be influenced by many factors such as the availability of social support, employment, financial, where you live, severity of the disability, ability to participate in life roles (Müller et al., 2017; Geyh et al., 2010, Rivers et al., 2018) .On the same note, mental health is also is affected by the number of SHCs and the level of functioning (Rivers et al., 2018). Thus, when developing an intervention, it is important to consider multiple factors that can affect the individual's QoL and mental health state. For example, an intervention for people with SCI was conducted in Bangladesh by Hossain et al., (2020). The intervention included frequent telephonic contact, and occasional in-person contact with a health professional over a two-year period following discharge from hospital. The evaluation of the study found that the model of care used was not effective in preventing SHCs, death or secondary outcomes such as QoL in the two years post discharge from hospital. The stated reasons for the failure of the intervention were because of financial strain, poverty, lack of employment opportunities, societal attitudes, and inaccessible environments (Liu et al., 2020). Another study by Chishtie et al., (2018), conducted in Pakistan looked at SCI care specifically regarding pressure sore prevention. The study used diverse strategies such as health education, home visitation, peer to peer support and exercises. The evaluation of the study found that the model of care was effective, as all participants were able to identify pressure sores and the majority did not develop pressure sores (Chishtie et al., 2018). It

is important to highlight that the intervention by Chishtie et al., (2018), was developed to match the individual patient's needs. This emphasises the importance of patient centred care. Patient centred care promotes collaboration with the patient and the caregivers when developing interventions. Future studies can use participatory action research when exploring unmet needs and possible strategies to address the needs.

CHAPTER 8

CONCLUSION

This chapter will summarise the study findings, state the study limitations and the recommendations.

8.1 Study finding

This study found the following:

- The experience of bowel and bladder problems are frustrating and people with SCI lack control of these secondary health conditions(SHCs).
- People with SCI are dissatisfied with their sexual health and people with SCI find sexual problems worrisome.
- Sexual, bowel and bladder problems affect relationships and mental health.
- The effectiveness of the health intervention was not significant in changing perceived mental health and quality of life (QoL) in people with SCI.

8.2 Recommendations

Based on the study findings the following the research recommends,

Policy: Health planning for the needs of people with SCI is needed to ensure access to relevant health information, medication, proper toileting facilities, quality catheters and overall care support.

Research: Further research is required to determine ways to strengthen bowel, bladder, and sexual care for people with SCI, improve the problem and meet their long-term care needs.

Practice: Bowel and bladder education should ideally be part of rehabilitation for people with SCI. Rehabilitation health professionals must not neglect to focus on sexual counselling as well as educating people with SCI on sexual health and alternative sexual pleasure methods. There is

a need for health education focusing on factors that increase the risk of developing SHCs as well as introduce ways to maintain good intimate relationships with partners of people living with SCI.

8.3 Limitations of the study

The findings of this study cannot be generalised because a small population was used. Most of the participants were primarily men, paraplegic and had traumatic spinal cord injury. Although this represents the general SCI prevalence, a diversity of SCI profiles would have made for a more diverse response from participants. The educational programme could have been adjusted to target more knowledge retention than the effect on QoL and mental health. The study was also conducted in rural South Africa, findings in urban areas may differ as social circumstances may be different.

REFERENCES

AbilityLab, 2020. Rehabilitation Measures- WHO Quality of Life- BREF. Shirley Ryan Ability Lab, Chicago.

Available at:

https://www.sralab.org/rehabilitation-measures/short-form-12-item-version-2-health-survey
[Accessed: 7 August 2021]

Abrams P, Cardozo, L, Wagg, A, Wein, A. (Eds) Incontinence 6th Edition (2017). ICI-ICS. International Continence Society, Bristol UK, ISBN: 9780956960733. Available at: https://www.ics.org/publications/ici_6/Incontinence_6th_Edition_2017_eBook_v2.pdf
[Accessed: 20 October 2022]

Adriaansen, J. J., Post, M. W., de Groot, S., van Asbeck, F. W., Stolwijk-Swüste, J. M., Tepper, M., & Lindeman, E. (2013). Secondary health conditions in persons with spinal cord injury: a longitudinal study from one to five years post-discharge. *Journal of rehabilitation medicine*, *45*(10), 1016–1022. https://doi.org/10.2340/16501977-1207.

Adriaansen, J. J., Ruijs, L. E., van Koppenhagen, C. F., van Asbeck, F. W., Snoek, G. J., van Kuppevelt, D., Visser-Meily, J. M., & Post, M. W. (2016). Secondary health conditions and quality of life in persons living with spinal cord injury for at least ten years. *Journal of rehabilitation medicine*, *48*(10), 853–860. https://doi.org/10.2340/16501977-2166

Ahuja, C. S., Wilson, J. R., Nori, S., Kotter, M. R. N., Druschel, C., Curt, A., & Fehlings, M. G. (2017). Traumatic spinal cord injury. *Nature reviews. Disease primers*, *3*, 17018. https://doi.org/10.1038/nrdp.2017.18

Aikman, K., Oliffe, J. L., Kelly, M. T., & McCuaig, F. (2018). Sexual Health in Men With Traumatic Spinal Cord Injuries: A Review and Recommendations for Primary Health-Care Providers. American Journal of Men's Health, 12(6), 2044–2054. https://doi.org/10.1177/1557988318790883

Alexander, M., Courtois, F., Elliott, S., & Tepper, M. (2017). Improving Sexual Satisfaction in Persons with Spinal Cord Injuries: Collective Wisdom. Topics in Spinal Cord Injury Rehabilitation, 23(1), 57–70. https://doi.org/10.1310/sci2301-57

Alizadeh, A., Dyck, S. M. and Karimi-Abdolrezaee, S. (2019). Traumatic Spinal Cord Injury: An Overview of Pathophysiology, Models and Acute Injury Mechanisms. Frontiers in Neurology, 10:282. https://doi.org/10.3389/fneur.2019.00282.

Alsulihem A, Corcos, 2019. Evaluation, treatment, and surveillance of neurogenic detrusor over activity in spinal cord injury patients. Neuroimmunol Neuroinflammation; 6:13. http://dx.doi.org/10.20517/2347-8659.2019.007

Anjum, A., Yazid, M. D., Fauzi Daud, M., Idris, J., Ng, A. M. H., Selvi Naicker, A., Ismail, O. H. R., Athi Kumar, R. K., & Lokanathan, Y. (2020). Spinal Cord Injury: Pathophysiology, Multimolecular Interactions, and Underlying Recovery Mechanisms. *International journal of molecular sciences*, *21*(20), 7533. https://doi.org/10.3390/ijms21207533.

Bauer SR, Breyer BN, Stampfer MJ, Rimm EB, Giovannucci EL, Kenfield SA. (2020). Association of Diet With Erectile Dysfunction Among Men in the Health Professionals Follow-up Study. JAMA Netw Open. 2020 Nov 2;3(11):e2021701. Doi: 10.1001/jamanetworkopen.2020.21701. PMID: 33185675; PMCID: PMC7666422.

Bernardi M, Fedullo AL, Bernardi E, Munzi D, Peluso I, Myers J, Lista FR, Sciarra T. (2020). Diet in neurogenic bowel management: a viewpoint on spinal cord injury. World J Gastroenterol. 2020;26(20):2479–97. https://doi.org/10.3748/wjg.v26.i20.2479.

Berwick, D.M., Murphy, J.M., Goldman, P.A. 1991, Performance of a five-item mental health screening test. Med Care, 29, pp. 169-176

Bladder management options following SCI. Available at:

https://msktc.org/sci/factsheets/bladder-management-options-following-sci [Accessed: 20 April 2022]

Bowel management options following SCI. Available at:

https://msktc.org/sci/factsheets/bowel-function-after-spinal-cord-injury [Accessed: 20 April 2022]

Braaf, S, Lennox, A, Nunn, A & Gabbe, B. (2017). Social activity and relationship changes experienced by people with bowel and bladder dysfunction following spinal cord injury. Spinal Cord. 55(7):679–686. doi.org/10.1038/sc.2017.19.

Brinkhof, M. W. G., Al-Khodairy, A., Eriks-Hoogland, I., Fekete, C., Hinrichs, T., Hund-Georgiadis, M., Meier, S., Scheel-Sailer, A., Schubert, M., Reinhardt, J. D., & SwiSCI Study Group. (2016). Health conditions in people with spinal cord injury: Contemporary evidence from a population-based community survey in Switzerland. Journal of Rehabilitation Medicine, 48(2), 197–209. https://doi.org/10.2340/16501977-2039

Budd, M. A., Gater, D. R., Jr, & Channell, I. (2022). Psychosocial Consequences of Spinal Cord Injury: A Narrative Review. Journal of personalized medicine, 12(7), 1178. https://doi.org/10.3390/jpm12071178

Burke, D., Fullen, B., Stokes, D and Lennon, O. (2016). Neuropathic pain prevalence following spinal cord injury: A systematic review and meta-analysis. European journal of pain (London, England). 21.10.1002/ejp.905.

Burns, A. S., Marino, R. J., Kalsi-Ryan, S., Middleton, J. W., Tetreault, L. A., Dettori, J. R., Mihalovic, K. E. and Fehlings, M. G. (2017). Type and Timing of Rehabilitation Following Acute and Subacute Spinal Cord Injury: A Systematic Review. Global Spine Journal, 7(3S): 175S-194S. https://doi.org/10.1177/2192568217703084.

Callaway, L., Barclay, L., McDonald, R., Farnworth, L., & Casey, J. (2015). Secondary health conditions experienced by people with spinal cord injury within community living: Implications for a National Disability Insurance Scheme. Australian Occupational Therapy Journal, 62(4), 246–254. https://doi.org/10.1111/1440-1630.12206

Callaway, L., Enticott, J., Farnworth, L., McDonald, R., Migliorini, C., & Willer, B. (2017). Community integration outcomes of people with spinal cord injury and multiple matched controls: A pilot study. Australian Occupational Therapy Journal, 64(3), 226–234. https://doi.org/10.1111/1440-1630.12350

Chen, Y, He, Y & DeVivo, MJ. (2016). Demographic and Injury Trends of Traumatic Spinal Cord Injuries in the United States 1972-2014. Archives of Physical Medicine and Rehabilitation. 97(10):e6–e7. doi.org/10.1016/j.apmr.2016.08.016.

Chishtie, J., Chishtie, F., Yoshida, K and Balogh, R. (2019) Spinal cord injury rehabilitation and pressure ulcer prevention after the 2005 South Asian Earthquake: a CBR case study from Pakistan, Disability and Rehabilitation, 41:14, 1655-1663, DOI: 10.1080/09638288.2018.1445783

Couillard-Despres, Sebastien & Bieler, Lara & Vogl, Michael. (2017). Pathophysiology of Traumatic Spinal Cord Injury. 10.1007/978-3-319-46293-6_19.

Courtois, F., & Charvier, K. (2015). Sexual dysfunction in patients with spinal cord lesions. Handbook of Clinical Neurology, 130, 225–245. https://doi.org/10.1016/B978-0-444-63247-0.00013-4

Dimitrijevic, Milan & Krenn, Matthias. (2016). Human Spinal Cord Motor Control That is Partially or Completely Disconnected from the Brain. American Journal of Neuroprotection and Neuroregeneration. 8. 12-26. 10.1166/ajnn.2016.1120.

Dorsher, P. T., & McIntosh, P. M. (2012). Neurogenic bladder. Advances in urology, 2012, 816274. https://doi.org/10.1155/2012/816274

Draulans, N., Kiekens, C., oles, E. and Peers, K. (2011). Etiology of Spinal Cord Injuries in SubSaharan Africa. Spinal Cord, 49: 1148-1154. https://doi.org/10.1038/sc.2011.93.

Earle S, O'Dell L, Davies A, Rixon A. (2020). Views and experiences of sex, sexuality and relationships following spinal cord injury: a systematic review and narrative syntheses of the qualitative literature. Sex Disabil. 2020;38:567–95. https://doi.org/10.1007/s11195-020-09653-0.

El-Masri, W. S., Chong, T., Kyriakider, A. E., & Wang, D. (2012). Long-term follow-up study of outcomes of bladder management in spinal cord injury patients under the care of the Midlands Centre for Spinal Injuries in Oswestry. *Spinal cord*, *50*(1), 14–21. https://doi.org/10.1038/sc.2011.78

Elmelund, M., Klarskov, N., & Biering-Sørensen, F. (2018). Prevalence of urinary incontinence in women with spinal cord injury. Spinal Cord, 56(12), 1124–1133. https://doi.org/10.1038/s41393-018-0157-0

Emmanuel A., 2019, Neurogenic bowel dysfunction [version 1; peer review: 2 approved] F1000Research 2019, 8(F1000 Faculty Rev):1800

Emos MC, Agarwal S. Neuroanatomy, Upper Motor Neuron Lesion. [Updated 2022 Aug 22]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022 Jan-. Available at: https://www.ncbi.nlm.nih.gov/books/NBK537305/.

Evardone, M, Wilson, CS, Weinel, D, Soble, JR & Kang, Y. (2018a). Does attendance in SCI education courses impact health outcomes in acute rehabilitation? Journal of Spinal Cord Medicine. 41(1):17–27. doi.org/10.1080/10790268.2016.1177269.

Fehlings, M. G., Tetreault, L. A., Wilson, J. R., Kwon, B. K., Burns, A. S., Martin, A. R., Hawryluk, G. and Harrop, J. S. (2017). A Clinical Practice Guideline for the Management of Acute Spinal Cord Injury: Introduction, Rationale and Scope. Global Spine Journal, 7(3S): 84S-94S. https://doi.org/10.1177/2192568217703387.

Furlan, J. C., Sakakibara, M. B., Miller, W. C. and Krassioukov, A. V. (2013). Global Incidence and Prevalence of Traumatic Spinal Cord Injury. The Canadian Journal of Neurological Sciences, 40(4): 456-464. https://doi.org/10.1017/s0317167100014530.

Fuseini, A.-G., Aniteye, P., & Alhassan, A. (2019). Beyond the Diagnosis: Lived Experiences of Persons with Spinal Cord Injury in a Selected Town in Ghana. Neurology Research International, 2019, 9695740. https://doi.org/10.1155/2019/9695740

Ganle, J. K., Baatiema, L., Quansah, R., & Danso-Appiah, A. (2020). Barriers facing persons with disability in accessing sexual and reproductive health services in sub-Saharan Africa: A systematic review. PloS one, 15(10), e0238585. https://doi.org/10.1371/journal.pone.0238585

GBD 2016 Traumatic Brain Injury and Spinal Cord Injury Contributors (2018). Global, Regional and National Burden of Traumatic Brain Injury and Spinal Cord Injury, 1990-2016: A Systematic Analysis for the Global Burden of Disease Study 2016. The Lancet Neurology, 18(1): 56-87. https://doi.org/10.1016/S1474-4422(18)30415-0.

Geyh, S., Ballert, C., Sinnott, A., Charlifue, S., Catz, A., D'Andrea Greve, J. M., & Post, M. W. (2013). Quality of life after spinal cord injury: a comparison across six countries. *Spinal cord*, *51*(4), 322–326. https://doi.org/10.1038/sc.2012.128

Giannopapas, V., & Sg, P. (2020). ctA ctA YOung ScientiStS' pageS ctA ctA Spinal cord injury and Sexual health (Vol. 72).

Ginsberg D. (2013). The epidemiology and pathophysiology of neurogenic bladder. Am J Manag Care. 2013;19(10 Suppl):s191-6. PMID: 24495240.

Giurleo, C., McIntyre, A., Kras-Dupuis, A., & Wolfe, D. L. (2022). Addressing the elephant in the room: integrating sexual health practice in spinal cord injury rehabilitation. Disability and Rehabilitation, 44(13), 3245–3252. https://doi.org/10.1080/09638288.2020.1856949

Golestani, A., Shobeiri, P., Sadeghi-Naini, M., Jazayeri, S. B., Maroufi, S. F., Ghodsi, Z., Dabbagh Ohadi, M. A., Mohammadi, E., Rahimi-Movaghar, V., & Ghodsi, S. M. (2022). Epidemiology of Traumatic Spinal Cord Injury in Developing Countries from 2009 to 2020: A Systematic Review and Meta-Analysis. *Neuroepidemiology*, *56*(4), 219–239. https://doi.org/10.1159/000524867.

Guilcher, S.J.T., Craven, B.C., Lemieux-Charles, L., Casciaro, T., McColl, M.A. & Jaglal, S.B., (2013) 'Secondary health conditions and spinal cord injury: An uphill battle in the journey of care', *Disability and Rehabilitation* 35(11), 894-906. https://doi.org/10.3109/09638288.2012.721048

Guly, H. R., Bouamra, O., Lecky, F. E. & Trauma Audit and Research Network. (2008). The incidence of neurogenic shock in patients with isolated spinal cord injury in the emergency department. *Resuscitation* 76, 57–62. https://doi.org/10.1016/j.resuscitation.2007.06.008.

Hagen, E. M. (2015). Acute Complications of Spinal Cord Injury. World Journal of Orthopaedics, 6(1): 17-23. https://doi.org/10.5312/wjo.v6.i1.17.

Hagen, E.M and & Rekand, T, (2014). Management of bladder dysfunction and satisfaction of life after spinal cord injury in Norway, The Journal of Spinal Cord Medicine, 37:3, 310-316, DOI: 10.1179/2045772313Y.0000000171

Hagen, E.M., Rekand, T. (2015). Management of Neuropathic Pain Associated with Spinal Cord Injury. Pain Ther 4, 51–6. https://doi.org/10.1007/s40122-015-0033-y

Hajiaghababaei, M., Javidan, A. N., Saberi, H., Khoei, E. M., Khalifa, D. A., Koenig, H. G., & Pakpour, A. H. (2014). Female sexual dysfunction in patients with spinal cord injury: a study from Iran. Spinal Cord, 52(8), 646–649. https://doi.org/10.1038/sc.2014.99

Halvorsen A, Pape K, Post MWM, Biering-Sørensen F, Mikalsen S, Hansen AN, Steinsbekk A. (2021). Participation and quality of life in persons living with spinal cord injury in Norway. J Rehabil Med. 2021 Jul 15;53(7):jrm00217. doi: 10.2340/16501977-2858. PMID: 34232321; PMCID: PMC8638721.

Hanass-Hancock, J., Nene, S., Deghaye, N., & Pillay, S. (2017). "These are not luxuries, it is essential for access to life": Disability related out-of-pocket costs as a driver of economic vulnerability in South Africa. African Journal of Disability, 6, 280. https://doi.org/10.4102/ajod.v6i0.280

Harrow-Mortelliti, M., Reddy and Jimsheleishvili, G. (2022). Physiology, Spinal Cord. [Updated 2022 Jan 29]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022 Jan-. Available at: https://www.ncbi.nlm.nih.gov/books/NBK544267/ [Accessed: 31 October 2022]

Hashemi, G., Wickenden, M., Bright, T., Kuper, H. (2020). Barriers to accessing primary healthcare services for people with disabilities in low and middle-income countries, a Meta-synthesis of qualitative studies. Disabil Rehabil. 21:1-14. doi:10.1080/09638288.2020.1817984.

Henke, A. M., Billington, Z. J., & Gater, D. R., Jr (2022). Autonomic Dysfunction and Management after Spinal Cord Injury: A Narrative Review. Journal of personalized medicine, 12(7), 1110. https://doi.org/10.3390/jpm12071110

Hess, M. J., & Hough, S. (2012). Impact of spinal cord injury on sexuality: broad-based clinical practice intervention and practical application. The Journal of Spinal Cord Medicine, 35(4), 211–218. https://doi.org/10.1179/2045772312Y.0000000025

Ho, C., Atchison, K., Noonan, V. K., McKenzie, N., Cadel, L., Ganshorn, H., Rivera, J. M. B., Yousefi, C., & Guilcher, S. J. T. (2021). Models of Care Delivery from Rehabilitation to Community for Spinal Cord Injury: A Scoping Review. *Journal of neurotrauma*, *38*(6), 677–697. https://doi.org/10.1089/neu.2020.7396.

Hossain, MS, Harvey, LA, Islam, MS, Rahman, MA, Muldoon, S, Biering-Sorensen, F, Jan, S, Liu, H, (2020). A community-based intervention to prevent serious complications and death 2 years after discharge in people with spinal cord injury in Bangladesh (CIVIC): a randomised trial. Spinal Cord. 59(6):649–658. doi.org/10.1038/s41393-020-00546-9.

Hudon, Catherine & Fortin, Martin & Haggerty, Jeannie & Loignon, Christine & Lambert, Mireille & Poitras, Marie-Eve. (2012). Patient-centered care in chronic disease management: A thematic analysis of the literature in family medicine. Patient education and counseling. 88. 170-6. 10.1016/j.pec.2012.01.009

Hughes M. (2014). Bowel management in spinal cord injury patients. Clinics in colon and rectal surgery, 27(3), 113–115. https://doi.org/10.1055/s-0034-1383904

Ide-Okochi, A., Yamazaki, Y., Tadaka, E., Fujimura, K. & Kusunaga, T., (2013). 'Illness experience of adults with cervical spinal cord injury in Japan: A qualitative investigation', BMC Public Health 13(69), 1–10

January AM, Zebracki K, Chlan KM, Vogel LC. (2014). Mental health and risk of secondary medical complications in adults with pediatric-onset spinal cord injury. *Top Spinal Cord Inj Rehabil* 2014;20(1):1–12.

Jensen, M. P., Truitt, A. R., Schomer, K. G., Yorkston, K. M., Baylor, C. and Molton, I. R. (2013). Frequency and Age Effects of Secondary Health Conditions in Individuals with Spinal Cord Injury: A Scoping Review. Spinal Cord, 51(12): 882-892. https://doi.org/10.1038/sc.2013.112.

Joseph, C., & Nilsson Wikmar, L. (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. https://doi.org/10.1038/sc.2015.189

Joseph, C., Delcarme, A., Vlok, I., Wahman, K., Phillips, J. and Nilsson Wikmar, L. (2015). Incidence and Aetiology of Traumatic Spinal Cord Injury in Cape Town, South Africa: A 99 Prospective, Population-Based Study. Spinal Cord, 53: 692-696. https://doi.org/10.1038/sc.2015.51.

Joseph, Conran & Scriba, Ernst & Wilson, Virginia & Mothabeng, Joyce & Theron, Francois. (2017). People with Spinal Cord Injury in Republic of South Africa. American journal of physical medicine & rehabilitation / Association of Academic Physiatrists. 92. S109-S111. 10.1097/PHM.0000000000000594.

Kang, Y., Ding, H., Zhou, H., Wei, Z., Liu, L., Pan, D. and Feng, S. (2018). Epidemiology of Worldwide Spinal Cord Injury: A Literature Review. Journal of Neurorestoratology, 6: 1-9. https://doi.org/10.2147/jn.s143236.

Katoh, H., Yokota, K., & Fehlings, M. G. (2019). Regeneration of Spinal Cord Connectivity Through Stem Cell Transplantation and Biomaterial Scaffolds. *Frontiers in cellular neuroscience*, *13*, 248. https://doi.org/10.3389/fncel.2019.00248.

Khan YS, Lui F. Neuroanatomy, Spinal Cord. [Updated 2022 Jul 25]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2022 Jan-. Available at: https://www.ncbi.nlm.nih.gov/books/NBK559056/ [Accessed: 31 October 2022]

Khorasanizadeh, M., Yousefifard, M., Eskian, M., Lu, Y., Chalangari, M., Harrop, J. S., Jazayeri, S. B., Seyedpour, S., Khodaei, B., Hosseini, M., & Rahimi-Movaghar, V. (2019). Neurological recovery following traumatic spinal cord injury: a systematic review and meta-analysis. *Journal of neurosurgery. Spine*, 1–17. Advance online publication. https://doi.org/10.3171/2018.10.SPINE18802.

Krassioukov, A., Eng, J. J., Claxton, G., Sakakibara, B. M., & Shum, S. (2010). Neurogenic bowel management after spinal cord injury: A systematic review of the evidence. In Spinal Cord (Vol. 48, Issue 10, pp. 718–733). https://doi.org/10.1038/sc.2010.14

Kurze, I, Geng, V & Böthig, R. (2022). Guideline for the management of neurogenic bowel dysfunction in spinal cord injury/disease. Spinal Cord. 60(5):435–443. doi.org/10.1038/s41393-022-00786-x.

Le, J., & Dorstyn, D. (2016). Anxiety prevalence following spinal cord injury: a meta-analysis. *Spinal cord*, *54*(8), 626. https://doi.org/10.1038/sc.2016.69.

Liao, L., & Zhang, Z. (2014). Risk factors predicting upper urinary tract deterioration in patients with spinal cord injury: A prospective study. Spinal Cord, 52(6), 468–471. https://doi.org/10.1038/sc.2014.63

Liu H, Hossain MS, Islam MS, Rahman MA, Costa PD, Herbert RD, Jan S, Cameron ID, Muldoon S, Chhabra HS, Lindley RI, Biering-Sorensen F, Ducharme S, Taylor V, Harvey LA. (2020). Understanding how a community-based intervention for people with spinal cord injury in Bangladesh was delivered as part of a randomised controlled trial: a process evaluation. Spinal Cord. Nov;58(11):1166-1175. doi: 10.1038/s41393-020-0495-6.

Lofland, J. (1971). Analyzing social settings. Belmont, CA: Wadsworth.

Lombardi, G., Del Popolo, G., Macchiarella, A., Mencarini, M., Celso, M. (2010). Sexual rehabilitation in women with spinal cord injury: a critical review of the literature. Spinal Cord. 48(12):842-9. doi: 10.1038/sc.2010.36. Epub 2010 Apr 13. PMID: 20386552.

Lynch, A.C, Antony A, Dobbs B.R, (2001). Frizelle FA. Bowel dysfunction following spinal cord injury. Spinal Cord. 39(4):193-203. doi: 10.1038/sj.sc.3101119. PMID: 11420734.

Maart, S. & Jelsma., J. (2014) Disability and access to health care – a community based descriptive study, Disability and Rehabilitation, 36:18 1489-1493

Madasa, V., Boggenpoel, B., Phillips, J., & Joseph, C. (2020). Mortality and secondary complications four years after traumatic spinal cord injury in Cape Town, South Africa. Spinal Cord Series and Cases, 6(1), 84. https://doi.org/10.1038/s41394-020-00334-w

Mashola, M. K. and Mothabeng, D. J. (2019). Associations Between Health Behaviour, Secondary Health Conditions and Quality of Life in People with Spinal Cord Injury. African Journal of Disability, 8(0): a463. https://doi.org/10.4102/ajod.v8i0.463.

Mashola, M. K., Korkie, E., & Mothabeng, D. J. (2021). Pain and its impact on functioning and disability in manual wheelchair users with spinal cord injury: a protocol for a mixed-methods study. BMJ open, 11(1), e044152. https://doi.org/10.1136/bmjopen-2020-044152

Mashola, M. K., Olorunju, S. A. S. and Mothabeng, J. (2019). Factors Related to Hospital Readmissions in People with Spinal Cord Injury. South African Medical Journal, 109(2): 107-111. https://doi.org/10.7196/samj.2019.v109i2.13344.

Mashola, MK & Mothabeng, DJ. (2019). African Journal of Disability Introduction Problem statement. doi.org/10.4102/ajod.

Merriam, S.B. (1998). Qualitative research and case study applications in education. San Francisco: Jossey-Bass Publishers

Miles, M. B., & Huberman, A. M. (1994). Qualitative data analysis: An expanded sourcebook. Thousand Oaks, CA: Sage Publications, Inc

Morse, J.M. (2016). Mixed Method Design: Principles and Procedures (1st ed.). Routledge. https://doi.org/10.4324/9781315424538

Müller, R., Landmann, G., Béchir, M., Hinrichs, T., Arnet, U., Jordan, X., & Brinkhof, M. W. G. (2017). Chronic pain, depression and quality of life in individuals with spinal cord injury:

Mediating role of participation. *Journal of rehabilitation medicine*, *49*(6), 489–496. https://doi.org/10.2340/16501977-2241

Munce, Sarah & Webster, Fiona & Fehlings, Michael & Straus, Sharon & Jang, Eunice & Jaglal, Susan. (2014). Perceived facilitators and barriers to self-management in individuals with traumatic spinal cord injury: A qualitative descriptive study. BMC neurology. 14. 48. 10.1186/1471-2377-14-48.

Musubire, A.K., Meya, D.B., Katabira, E.T. *et al.* Epidemiology of non-traumatic spinal cord injury in Uganda: a single center, prospective study with MRI evaluation. *BMC Neurol* 19, 10 (2019). https://doi.org/10.1186/s12883-019-1236-3.

National Institute of Mental Health (2022). Definition of Prevalence. Available at: https://www.nimh.nih.gov/health/statistics/what-is-prevalence [Accessed; 2 January 2023]

Ndzamela, S & Burton, S. (2020). 2739-Article Text-19245-1-10-20201028 (1). South African Pharmaceutical Journal . 87(5). Available from: sapj.co.za/index.php/SAPJ/article/view/2739 [Accessed 20 October 2022].

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and policy in mental health*, *42*(5), 533–544. https://doi.org/10.1007/s10488-013-0528-y

Parittotokkaporn,S., Varghese.C., O'Grady, G., Svirskis, D., Subramanian, S., O'Carroll S.J., (2020). Non-invasive neuromodulation for bowel, bladder and sexual restoration following spinal cord injury: A systematic review, Clinical Neurology and Neurosurgery,Volume 194

Park, S. E., Elliott, S., Noonan, V. K., Thorogood, N. P., Fallah, N., Aludino, A., & Dvorak, M. F. (2017). Impact of bladder, bowel and sexual dysfunction on health status of people with thoracolumbar spinal cord injuries living in the community. The Journal of Spinal Cord Medicine, 40(5), 548–559. https://doi.org/10.1080/10790268.2016.1213554

Patel, T, Milligan, J & Lee, J. (2017). Medication-related problems in individuals with spinal cord injury in a primary care-based clinic. Journal of Spinal Cord Medicine. 40(1):54–61. doi.org/10.1179/2045772315Y.0000000055.

Pavese, C, Bachmann, LM, Schubert, M, Curt, A, Mehnert, U, Schneider, MP, Scivoletto, G, Finazzi Agrò, E, (2019). Bowel Outcome Prediction After Traumatic Spinal Cord Injury: Longitudinal Cohort Study. Neurorehabilitation and Neural Repair. 33(11):902–910. doi.org/10.1177/1545968319868722.

Pavese, Chiara, and Thomas M. Kessler. 2023. "Prediction of Lower Urinary Tract, Sexual, and Bowel Function, and Autonomic Dysreflexia after Spinal Cord Injury" Biomedicines 11, no. 6:1644. https://doi.org/10.3390/biomedicines11061644

Pefile, N., Mothabeng, J. D. and Naidoo, S. (2018). Profile of Patients with Spinal Cord Injuries in Kwazulu-Natal, South Africa: Implications for Vocational Rehabilitation. The Journal of Spinal Cord Medicine, 42(2):1-10. https://doi.org/10.1080/10790268.2018.1428264

Pelosi, G., Faleiros, F., Pereira, M. R. C., Bimbatti, K. de F., & Tholl, A. D. (2021). Study on the prevalence of neurogenic bladder in Brazilians with traumatic and non-traumatic spinal cord injury. The Journal of Spinal Cord Medicine, 1–5. https://doi.org/10.1080/10790268.2021.1981715

Piatt, JA, Nagata, S, Zahl, M, Li, J & Rosenbluth, JP. (2016). Problematic secondary health conditions among adults with spinal cord injury and its impact on social participation and daily life. Journal of Spinal Cord Medicine. 39(6):693–698. Doi.org/10.1080/10790268.2015.1123845.

Pilusa, S, Myezwa, H & Potterton, J. (2020). Prevention strategies for secondary health conditions in people with spinal cord injury: A scoping review protocol. JBI Evidence Synthesis. 18(3):626–632. doi.org/10.11124/JBISRIR-D-18-00015.

Pilusa, S, Myezwa, H & Potterton, J. (2021). Secondary health conditions in people with spinal cord injury in South Africa: Prevalence and associated factors. South African Medical Journal. 111(12):1211. doi.org/10.7196/SAMJ.2021.v111i12.15761.

Pilusa, S. I., Myezwa, H. and Potterton, J. (2021). Experiences of Secondary Health Conditions Amongst Persons with Spinal Cord Injury in South Africa: A Qualitative Study. South African Journal of Physiotherapy, 77(1): a1530. https://doi.org/10.4102/sajp.v77i1.1530.

Pilusa, S., Myezwa, H. & Potterton, J., (2019), Prevention care for secondary health conditions among people living with spinal cord injuries: research protocol. BMC ResNotes 12, 179

Pilusa, S., Myezwa, H. & Potterton, J., (2021), Experiences of secondary health conditions amongst people spinal cord injury in South Africa: A qualitative study. South Africa Journal of Physiotherapy 77(1)

Pilusa, S., Myezwa, H., & Potterton, J. (2022). Views of health care users and providers: Solutions to improve the prevention of secondary health conditions among people with spinal

cord injury, South Africa. Spinal Cord Series and Cases, 8(1), 67. https://doi.org/10.1038/s41394-022-00530-w

Rand Corporation, 2021. 12 Item Short Survey (SF12). Rand Corporation, California

Richardson, A., Samaranayaka, A., Sullivan, M., & Derrett, S. (2021). Secondary health conditions and disability among people with spinal cord injury: A prospective cohort study. Journal of Spinal Cord Medicine, 44(1), 19–28. https://doi.org/10.1080/10790268.2019.1581392

Rimmer, J. H, Chen, M. -D. and Hsieh, K. (2011). A Conceptual Model for Identifying, Preventing and Managing Secondary Health Conditions in People with Disabilities. Physical Therapy, 91(12): 1728-1739. https://doi.rg/10/2522/ptj.20100410

Rogers, W. K., & Todd, M. (2016). Acute spinal cord injury. *Best practice & research. Clinical anaesthesiology*, *30*(1), 27–39. https://doi.org/10.1016/j.bpa.2015.11.003

Savic, G, Devivo, MJ, Frankel, HL, Jamous, MA, Soni, BM & Charlifue, S. (2017). Long-term survival after traumatic spinal cord injury: A 70-year British study. Spinal Cord. 55(7):651–658. doi.org/10.1038/sc.2017.23.

Schultz, K.R., Mona, L.R. & Cameron, R.P. (2022). Mental Health and Spinal Cord Injury: Clinical Considerations for Rehabilitation Providers. *Curr Phys Med Rehabil Rep* 10, 131–139 (2022). https://doi.org/10.1007/s40141-022-00349-4.

Sezer, N., Akkuş, S., & Uğurlu, F. G. (2015). Chronic complications of spinal cord injury. World journal of orthopedics, 6(1), 24–33. https://doi.org/10.5312/wjo.v6.i1.24

Singh, A., Tetreault, L., Kalsi-Ryan, S., Nouri, A. and Fehlings, M. G. (2014). Global Prevalence and Incidence of Spinal Cord Injury. Clinical Epidemiology, 6: 309-331. https://doi.org/10.2147/clep.s68889.

Stothers, L., Macnab, A. J., Mukisa, R., Mutabazi, S., & Bajunirwe, F. (2017). Traumatic spinal cord injury in Uganda: a prevention strategy and mechanism to improve home care. *International journal of epidemiology*, *46*(4), 1086–1090. https://doi.org/10.1093/ije/dyx058.

Stratton, S. (2019). Quasi-Experimental Design (Pre-Test and Post-Test Studies) in Prehospital and Disaster Research. *Prehospital and Disaster Medicine, 34*(6), 573-574. doi:10.1017/S1049023X19005053

Strauss, A. M., & Corbin, J. (1998). Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. (3rd Edition.). Newbury Park, CA: Sage Publications, Inc.

Strøm, V., Månum, G., Arora, M., Joseph, C., Kyriakides, A., le Fort, M., Osterthun, R., Perrouin-Verbe, B., Postma, K., & Middleton, J. (2022). Physical Health Conditions in Persons with Spinal Cord Injury Across 21 Countries Worldwide. *Journal of Rehabilitation Medicine*, *54*, jrm00302. https://doi.org/10.2340/jrm.v54.2040

Tate, D. G., Forchheimer, M., Rodriguez, G., Chiodo, A., Cameron, A. P., Meade, M., & Krassioukov, A. (2016). Risk Factors Associated With Neurogenic Bowel Complications and Dysfunction in Spinal Cord Injury. Archives of Physical Medicine and Rehabilitation, 97(10), 1679–1686. https://doi.org/10.1016/j.apmr.2016.03.019

Taweel W.A., Seyam R, (2015). Neurogenic bladder in spinal cord injury patients. Res Rep Urol.10;7:85-99. doi: 10.2147/RRU.S29644. PMID: 26090342; PMCID: PMC4467746

Taylan, S., Özkan, İ., & Küçükakça Çelik, G. (2022). Experiences of patients and their partners with sexual problems after spinal cord injury: A phenomenological qualitative study. The Journal of Spinal Cord Medicine, 45(2), 245–253. https://doi.org/10.1080/10790268.2020.1798136

Tederko, P., Krasuski, T., Krasuski, M., Długołęcka, A., & Tarnacka, B. (2017). Determinants of health knowledge and health perceptions from the perspective of health-related education of patients with spinal cord injury: a systematic review. *International journal of rehabilitation research. Internationale Zeitschrift fur Rehabilitationsforschung. Revue internationale de recherches de readaptation*, *40*(2), 97–106. https://doi.org/10.1097/MRR.0000000000000215

Thabane, L., Ma, J., Chu, R., Cheng, J., Ismaila, A., Rios, L. P., Robson, R., Thabane, M., Giangregorio, L., & Goldsmith, C. H. (2010). A tutorial on pilot studies: What, why and how. In BMC Medical Research Methodology (Vol. 10). https://doi.org/10.1186/1471-2288-10-1

Tran A.P., Warren P.M., Silver J. (2018). The biology of regeneration failure and success after spinal cord injury. *Physiol. Rev.* 2018;98:881–917. https://doi.org/10.1152/physrev.00017.2017.

Turtle J.D., Henwood M.K., Strain M.M., Huang Y.J., Miranda R.C., Grau J.W. (2019). Engaging pain fibers after a spinal cord injury fosters hemorrhage and expands the area of secondary injury. *Exp. Neurol.* 2019;311:115–124. https://doi.org/10.1016/j.expneurol.2018.09.018.

United Nations, 2011. Workplace mental health and well-being strategy. Understanding Mental Health. Available at: https://www.un.org/en/healthyworkforce/files/Understanding%20Mental%20Health.pdf [Accessed: 10 November 2022]

van der Meer P, Post MW, van Leeuwen CM, van Kuppevelt HJ, Smit CA, van Asbeck FW., (2017), Impact of health problems secondary to SCI one and five years after first inpatient rehabilitation. Spinal Cord; 55(1):98-104. doi: 10.1038/sc.2016.103. Epub 2016 Jul 19. PMID: 27431661.

Vassar M, Matthew H. (2013). The retrospective chart review: important methodological considerations. J Educ Eval Health Prof. 2013;10.12. doi: 10.3352/jeehp.2013.10.12

Venkatesh, K., Ghosh, S. K., Mullick, M., Manivasagam, G., & Sen, D. (2019). Spinal cord injury: pathophysiology, treatment strategies, associated challenges, and future implications. *Cell and tissue research*, *377*(2), 125–151. https://doi.org/10.1007/s00441-019-03039-1

Wahman, K., Nilsson Wikmar, L., Chlaidze, G., & Joseph, C. (2019). Secondary medical complications after traumatic spinal cord injury in Stockholm, Sweden: Towards developing prevention strategies. Journal of Rehabilitation Medicine, 51(7), 513–517. https://doi.org/10.2340/16501977-2568

Ware, J.E. (1995). SF-12: How to Score the SF-12 Physical and Mental Health Summary Scores. The Health Institute, New England Medical Center, Boston, Massachusetts

Wheeler, T. L., Bowel and Bladder Workshop Participants, de Groat, W., Eisner, K., Emmanuel, A., French, J., Grill, W., Kennelly, M. J., Krassioukov, A., Gallo Santacruz, B., Biering-Sørensen, F., & Kleitman, N. (2018). Translating promising strategies for bowel and bladder management in spinal cord injury. Experimental neurology, 306, 169–176. https://doi.org/10.1016/j.expneurol.2018.05.006

Whitehurst, D. G., Engel, L., & Bryan, S. (2014). Short Form health surveys and related variants in spinal cord injury research: a systematic review. *The journal of spinal cord medicine*, *37*(2), 128–138. https://doi.org/10.1179/2045772313Y.0000000159

Williams, R., & Murray, A. (2015). Prevalence of depression after spinal cord injury: a meta-analysis. *Archives of physical medicine and rehabilitation*, *96*(1), 133–140. https://doi.org/10.1016/j.apmr.2014.08.016.

World Health Organization (1994). Tools and Kits: WHOQOL: Measuring Quality of Life. Geneva: World Health Organization. Available at: https://www.who.int/tools/whoqol [Accessed: 12 August 2022].

World Health Organization (1998). Health Topics: Health Promotion. Geneva: World Health Organization. Available at: https://www.who.int/health-topics/health-promotion [Accessed: 29 October 2022].

World Health Organization (2012). Definition of Quality of Life. Available at: https://www.who.int/tools/whoqol [Accessed: 2 January 2023]

World Health Organization (2013). Fact Sheets: Spinal Cord Injury. Geneva: World Health Organization. Available at: https://www.who.int/news-room/fact-sheets/detail/spinal-cord-injury. [Accessed: 12 August 2022].

World Health Organization (2015). Sexual health, human rights, and the law. Geneva (Switzerland): World Health Organization. Available at: https://apps.who.int/iris/handle/10665/175556 [Accessed: 2 January 2023].

World Health Organization (2020). Definition of mental health. Available at: https://www.health.state.mn.us/communities/mentalhealth/index.html [Accessed: 2 January 2023]

World Health Organization (2023). Pan American Health Organization: Mental Health. Geneva: World Health Organization. Available at: https://www.paho.org/en/topics/mental-health. [Accessed: 2 January 2023].

Zürcher C, Tough H, Fekete C; SwiSCI Study Group. (2019). Mental health in individuals with spinal cord injury: The role of socioeconomic conditions and social relationships. PLoS One. Feb 20;14(2): e0206069. https://doi.org/10.1371/journal.pone.0206069

APPENDICES

Appendix 1a: Permission Letter to Conduct Research at Siletha Ithemba

Project Title: *Experience of Bowel, Bladder and Sexual Problems and the effectiveness of a health program on quality of Life and mental health in people with SCI in Manguzi.*

Dear CEO of Siletha Ithemba NPO,

I, Lauren Tomes, an MSc Physiotherapy student at the University of the Witwatersrand. I am doing a research study on the experience of bowel, bladder, and sexual dysfunction in people with spinal cord injury and the effectiveness of a health program on their mental health and quality of life.

The Study Research Objectives are:

1. Explore the experience of bowel and bladder dysfunction as well as sexual health problems in people with spinal cord injury (SCI)
2. Identify long-term care needs related to bowel, bladder, and sexual dysfunction in people with SCI.
3. To determine the effectiveness of the health program for bowel, bladder, and sexual dysfunction on quality of life (QoL).

4. To determine the effectiveness of the health program for bowel, bladder, and sexual dysfunction on mental health in people with spinal cord injury (SCI).

In this study, I want to learn more about experiences of bowel, bladder, sexual dysfunction in people with spinal cord injury (SCI) and the effectiveness of a health program on their quality of life and mental health. The findings of this study will therefore give us a better understanding of the SHCs experienced by people with SCI. Secondly, the findings of this study will inform care provided to people with SCI related to bowel, bladder as well as sexual health problems. I am aware that your rehabilitation staff have close relations with Siltha Ithemba NPO whom I have contacted as well to use their members as part of my sample study. This study findings will influence practice for, in terms of both physiotherapists and occupational therapists with effective therapeutic management of neurogenic bowel and bladder dysfunction as well as sexual health and hopefully long term this study could influence the management of long-term conditions in people with SCI as well as improve overall QoL of people living with SCI.

I am therefore requesting permission to use members of your organization as my sample study.

Your cooperation in this matter would be most highly appreciated.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Doctor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za.

The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za.

Sincerely,

Lauren Tomes

lauren.tomes351@gmail.com

0765888167

Appendix 1b: Permission Letter to Conduct Research at Manguzi Hospital

Project Title: *Experience of Bowel, Bladder and Sexual Problems and the effectiveness of a health program on quality of Life and mental health in people with SCI in Manguzi.*

Dear CEO of Manguzi Hospital,

I, Lauren Tomes, an MSc Physiotherapy student at the University of the Witwatersrand. I am doing a research study on the experience of bowel, bladder, and sexual dysfunction in people with spinal cord injury and the effectiveness of a health program on their mental health and quality of life.

The Study Research Objectives Are:

1. Explore the experience of bowel and bladder dysfunction as well as sexual health problems in people with spinal cord injury (SCI).
2. Identify long-term care needs related to bowel, bladder, and sexual dysfunction in people with SCI.
3. To assess the effectiveness of the health program for bowel, bladder, and sexual dysfunction on quality of life (QoL).

4. To assess the effectiveness of the health program for bowel, bladder, and sexual dysfunction on mental health in people with spinal cord injury (SCI).

In this study, I want to learn more about experiences of bowel, bladder, sexual dysfunction in people with spinal cord injury (SCI) and the effectiveness of a health program on quality of life and mental health. The findings of this study will therefore give us a better understanding of the SHCs experienced by people with SCI. Secondly, the findings of this study will inform care provided to people with SCI related to bowel, bladder as well as sexual health problems. I am aware that your rehabilitation staff have close relations with Siltha Ithemba NPO whom I have contacted as well to use their members as part of my sample study. This study findings will influence practice for, in terms of both physiotherapists and occupational therapists with effective therapeutic management of neurogenic bowel and bladder dysfunction as well as sexual health and hopefully long term this study could influence the management of long-term conditions in people with SCI as well as improve overall QoL of people living with SCI.

I am therefore requesting permission to use your facility as my research site.

Your cooperation in this matter would be most highly appreciated.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Doctor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za.

The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za.

Sincerely,

Lauren Tomes

lauren.tomes351@gmail.com

0765888167

Appendix 2a: Information Sheet - English

PARTICIPANT INFORMATION SHEET

Project Title: *Experience of Bowel, Bladder and Sexual Problems and the effectiveness of a health program on quality of Life and mental health in people with SCI in Manguzi.*

Dear Mr/Mrs/Miss,

I, Lauren Tomes, an MSc Physiotherapy student at the University of the Witwatersrand. I am doing a research study on the experience of bowel, bladder and sexual dysfunction in people with SCI and the effectiveness of a health program on their mental health and quality of life.

In this study, I want to learn more about experiences of bowel, bladder, sexual dysfunction in people with spinal cord injury (SCI) and the effectiveness of a health program on their quality of life and mental health. The findings of this study will therefore give us a better understanding of

the SHCs experienced by people with SCI. Secondly, the findings of this study will inform care provided to people with SCI related to bowel, bladder as well as sexual health problems.

This study findings will influence practice for, in terms of both physiotherapists and occupational therapists with effective therapeutic management of bowel and bladder dysfunction as well as sexual health and hopefully long term this study could influence the management of long-term conditions in people with SCI as well as improve overall quality of life (QoL) of people living with SCI.

People with SCI experience secondary health complications such as bladder and bowel and sexual health problems which need long-term care and support to prevent and manage them. Rehabilitation phase mainly focuses on activities of daily living neglecting long-term care needs for bowel, bladder, and sexual problems. Evidence shows that these problems are not adequately addressed. As such leaving people with SCI not knowing how to manage them and where to seek for health. In South Africa there is a lack of literature on the experience of people with SCI on bladder and bowel and sexual health problems and their management as well as how it affects both their mental health and QoL.

Who is eligible to take part in this study?

Participants over the age of 18 with spinal cord injuries will be recruited from the Siletha Ithemba NPO in Manguzi.

What will be involved in the study?

This study involves interviews facilitated with peer supporters in home language (isiZulu) to get a better understanding of the experiences you have with bowel, bladder and sexual problems as a

person living with SCI to establish how it affects your mental health and QoL. I will give you two questionnaires before we start the study looking at your mental health and QoL. The interview will take approximately 1-1.5 hours and will be audio recorded. The information you contribute should be accurate and detailed. A part of the study will also include a general check up with a Doctor to establish your current bowel and bladder management. We will have a group discussion where we will educate about bowel, bladder, and sexual problems and how to best manage them. Six weeks after the group discussion I will re-administer the same questionnaires to assess effectiveness of the health program on mental health and QoL.

Are there any risks of taking part in this study?

You will not be exposed to any risks and all COVID-19 precautions will be adhered to

What are the benefits of taking part in this study?

You will have an opportunity to highlight the challenges faced by people living with spinal cord injuries specifically with regards to bladder, bowel and sexual problems and help identify the gaps/needs in the health services especially when it comes to evidence based practice management and health promotion. Understanding how people living with a spinal cord injury experience complications and needs related to prevention can enable us to treat you more effectively if you should have problems. There are no monetary benefits.

Will information be handled as confidential?

In accordance with the new POPI Act to promote the protection of personal information efforts will be made to keep personal information confidential. Absolute confidentiality cannot be

guaranteed. Personal information may be disclosed if required by law. To ensure confidentiality of participants, each computer/laptop user will be assigned a study number.

The key to the study numbers assigned will be kept by the researcher only. Names of participants are only to be written on the consent form and not on the questionnaire.

Additionally, consent forms are to be kept separately from the questionnaires. All information will be used only for the purpose intended in this study only.

Participation is voluntary and refusal to participate will not involve any penalty or loss of benefits to which you are otherwise entitled. You may withdraw from this study at any time without suffering any repercussions.

I would be most grateful if you would be willing to participate in this research project and allow me access to your facility. This research could potentially create a bit more clarity and insight into this field. The project is scheduled to commence in February 2022 and finish in April 2022.

For more information, please contact me or my Research supervisor:

Miss Lauren Tomes, Principal Researcher. Tel no. 0765888167 or email lauren.tomes351@gmail.com

Mrs Sonti Pilusa, Research Supervisor. Tel no.0820536190 or 011 717 3715 or email

sonti.pilusa@wits.ac.za

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this

Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Doctor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za.

The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za.

Thank you for reading this Participant Information Sheet.

Appendix 2b: Information Sheet - Zulu

ISHIDI LOLWAZI LOMHLANGANISI

Isihloko Sephrojekthi: *Ukuba nakho Kwamathumbu, Isinye Nezinkinga Zocansi kanye nempumelelo yohlelo lwezempilo kwikhwalithi Yempilo nempilo yengqondo kubantu abane-SCI eManguzi.*

Mnuz/Nkk/Nkosazana othandekayo,

Mina, u-Lauren Tomes, umfundi we-MSc Physiotherapy eNyuvesi yaseWitwatersrand. Ngenza ucwaningo olumayelana nolwazi lwamathumbu, isinye kanye nokungasebenzi kahle kwezocansi kubantu abane-SCI kanye nempumelelo yohlelo lwezempilo empilweni yabo yengqondo kanye nezinga lempilo.

Kulolu cwaningo, ngifuna ukufunda kabanzi mayelana nokuhlangenwe nakho kwamathumbu, esinyeni, ukungasebenzi kahle kwezocansi kubantu abanokulimala komgogodla (SCI) kanye nempumelelo yohlelo lwezempilo kukhwalithi yabo yempilo nempilo yengqondo. Okutholwe

kulolu cwaningo ngakho-ke kuzosinika ukuqonda okungcono kwe-SHCS etholwa abantu abane-SCI. Okwesibili, okutholwe kulolu cwaningo kuzokwazisa ukunakekelwa okunikezwa abantu abane-SCI okuhlobene namathumbu, esinyeni kanye nezinkinga zempilo yezocansi.

Lokhu okutholwe ocwaningweni kuzoba nomthelela ekuzijwayezeni, ngokuya kwabo bobabili ama-physiotherapists kanye nabelaphi bomsebenzi abanokuphatha ngempumelelo ukungasebenzi kahle kwamathumbu nesinye kanye nempilo yezocansi futhi ngethemba lokuthi isikhathi eside lolu cwaningo lungaba nomthelela ekuphathweni kwezimo zesikhathi eside kubantu abane-SCI njengoba kanye nokuthuthukisa izinga lempilo jikelele (QoL) labantu abaphila ne-SCI.

Abantu abane-SCI bahlangabezana nezinkinga zempilo zesibili ezifana nesinye nesisu kanye nezinkinga zempilo yezocansi ezidinga ukunakekelwa isikhathi eside nokusekelwa ukuze zivinjwe futhi zizilawule. Isigaba sokubuyisela sigxile kakhulu emisebenzini yokuphila kwansuku zonke ngokunganaki izidingo zesikhathi eside zamathumbu, isinye, nezinkinga zocansi. Ubufakazi bukhombisa ukuthi lezi zinkinga azixazululwa ngendlela efanele. Kanjalo kushiya abantu abane-SCI bengazi ukuthi babaphathe kanjani futhi bafune kuphi impilo. ENingizimu Afrika kukhona ukushoda kwezincwadi mayelana nolwazi lwabantu abane-SCI ngezinkinga zesinye namathumbu kanye nempilo yocansi kanye nokuphathwa kwabo kanye nokuthi kuyithinta kanjani impilo yabo yengqondo kanye ne-QoL.

Ubani ofaneleka ukubamba iqhaza kulolu cwaningo?

Abazongenela lo mcimbi abaneminyaka engaphezu kuka-18 abalimele umgogodla bazothathwa eSiletha Ithemba NPO eManguzi.

Lolu cwaningo lubandakanya izingxoxo ezigqugquzelwe nabasekeli bontanga ngolimi lwasekhaya (isiZulu) ukuze uthole ukuqonda kangcono okuhlangenwe nakho kwakho

ngezinkinga zamathumbu, esinyeni kanye nezocansi njengomuntu ophila ne-SCI ukuthola ukuthi iyithinta kanjani impilo yakho yengqondo kanye ne-QoL. Ngizokunikeza imibuzo emibili ngaphambi kokuthi siqale ucwaningo sibheke impilo yakho yengqondo kanye ne-QoL. Inhlolokhono izothatha cishe amahora angu-1-1.5 futhi izorekhodwa umsindo. Ulwazi olunikelayo kufanele lunembile futhi lunemininingwane. Ingxenye yocwaningo izophinde ihlanganise nokuhlolwa okujwayelekile noDokotela ukuze kutholakale indlela ophethwe ngayo amathumbu nesinye. Sizoba nengxoxo yeqembu lapho sizofundisa khona ngezinkinga zamathumbu, esinyeni, nezocansi nokuthi ungazilawula kanjani kahle. Emavikini ayisithupha emva kwengxoxo yeqembu ngizophinda ngiphathe imibuzo efanayo

Yini ezobandakanywa ocwaningweni?

Lolu cwaningo lubandakanya izingxoxo ezigqugquzelwe nabasekeli bontanga ngolimi lwasekhaya (isiZulu) ukuze uthole ukuqonda kangcono okuhlangenwe nakho kwakho ngezinkinga zamathumbu, esinyeni kanye nezocansi njengomuntu ophila ne-SCI ukuthola ukuthi iyithinta kanjani impilo yakho yengqondo kanye ne-QoL. Ngizokunikeza imibuzo emibili ngaphambi kokuthi siqale ucwaningo sibheke impilo yakho yengqondo kanye ne-QoL. Inhlolokhono izothatha cishe amahora angu-1-1.5 futhi izorekhodwa umsindo. Ulwazi olunikelayo kufanele lunembile futhi lunemininingwane. Ingxenye yocwaningo izophinde ihlanganise nokuhlolwa okujwayelekile noDokotela ukuze kutholakale indlela ophethwe ngayo amathumbu nesinye. Sizoba nengxoxo yeqembu lapho sizofundisa khona ngezinkinga zamathumbu, esinyeni, nezocansi nokuthi ungazilawula kanjani kahle. Emavikini ayisithupha ngemva kwengxoxo yeqembu ngizophinda ngiphathe imibuzo efanayo ukuze ngihlole ukusebenza kahle kohlelo lwezempilo lwengqondo kanye neQoL.

Ingabe bukhona ubungozi bokubamba iqhaza kulolu cwaningo?

Ngeke utholakale kunoma yiziphi izingozi futhi zonke izinyathelo zokuphepha ze-COVID-19 zizolandelwa

Yiziphi izinzuzo zokubamba iqhaza kulolu cwaningo?

Uzothola ithuba lokugqamisa izinselelo ezibhekene nabantu abaphila nokulimala komgogodla ikakhulukazi maqondana nesinye, amathumbu kanye nezinkinga zocansi futhi usize ukukhomba izikhala/izidingo ezinsizeni zezempilo ikakhulukazi uma kuziwa ebufakazini bokulawulwa komkhuba kanye nokukhuthazwa kwezempilo. . Ukuqonda ukuthi abantu abaphila nokulimala komgogodla babhekana kanjani nezinkinga kanye nezidingo ezihlobene nokuvimbela kungasenza sikwazi ukukuphatha ngempumelelo uma kufanele ube nezinkinga. Azikho izinzuzo zemali.

Ingabe ulwazi luzophathwa njengoluyimfihlo?

Ngokuhambisana noMthetho omusha we-POPI wokukhuthaza ukuvikelwa kolwazi lomuntu siqu imizamo izokwenziwa ukugcina ulwazi lomuntu siqu luyimfihlo. Ukugcinwa kuyimfihlo okuphelele akunakuqinisekiswa. Ulwazi lomuntu siqu lungadalulwa uma kudingwa ngokomthetho. Ukuqinisekisa ukugcinwa kuyimfihlo kwabahlanganyeli, umsebenzisi ngamunye wekhompyutha/ikhompuyutha ephathekayo uzonikezwa inombolo yocwaningo. Ukhiye ezinambeni zocwaningo ezabelwe uzogcinwa umcwaningi kuphela. Amagama abahlanganyeli kufanele abhalwe efomini lemvume kuphela hhayi kuhlu lwemibuzo. Ukwengeza, amafomu emvume kufanele agcinwe ngokuhlukile kuhlu lwemibuzo. Lonke ulwazi luzosetshenziselwa kuphela inhloso ehloswe kulolu cwaningo kuphela.

Ukubamba iqhaza kuwukuzithandela futhi ukwenqaba ukubamba iqhaza angeke kuhilele noma iyiphi inhlawulo noma ukulahlekelwa yizinzuzo onegunya lazo ngenye indlela. Ungahoxa kulolu cwaningo nganoma yisiphi isikhathi ngaphandle kokuthola imiphumela

Ngingabonga kakhulu uma ungavuma ukubamba iqhaza kulo msebenzi wocwaningo futhi ungivumele ngifinyelele endaweni yakho. Lolu cwaningo lungase ludale ukucaca okwengeziwe kanye nokuqonda kulo mkhakha. Le phrojekthi ihlelelwe ukuthi iqale ngoFebruary 2022 futhi iphele ngoApril 2022.

Ukuze uthole ulwazi olwengeziwe ngicela ungithinte noma umqondisi wami Wocwaningo:

UNkosazana Lauren Tomes, Umcwaningi Oyinhloko. Inombolo yocingo. 0765888167 noma uthumele i-imeyili lauren.tomes351@gmail.com.

UNkk Sonti Pilusa, oyiNhloko yocwaningo. Tell no.0820536190 noma 011 717 3715 noma email sonti.pilusa@wits.ac.za.

Lolu cwaningo lugunyazwe yi-Human Research Ethics Committee (Medical) yaseNyuvesi yaseWitwatersrand, eGoli ("Committee"). Umsebenzi oyinhloko walokhu Ikomidi elokuvikela amalungelo nesithunzi sazo zonke izifundo zomuntu ezivuma ukubamba iqhaza kuphrojekthi yocwaningo ubuqotho bocwaningo.

Uma unokuthile okukukhathazayo ngendlela okwenziwa ngayo ucwaningo, sicela uthinte uSihlalo waleli Komidi onguDokotela Clement Penny, abangathintwa ngenombolo yocingo 011 717 2301, noma nge-imeyili ku- Clement.Penny@wits.ac.za.

Izinombolo zocingo zikanobhala weKomidi zithi 011 717 2700/1234 kanye namakheli e-imeyili ngu Zanele.Ndlovu@wits.ac.za kanye no Rhulani.Mukansi@wits.ac.za.

Siyabonga ngokufunda leli Shidi Lolwazi Lokufunda.

Appendix 3a: Participant Consent Form - English

PARTICIPANT CONSENT FORM

Project Title*:* *Experience of Bowel, Bladder and Sexual Problems and the effectiveness of a health program on quality of Life and mental health in people with SCI in Manguzi.*

1. I have been given a Participant Information Sheet which explains the nature and processes involved in this study, which is attached hereto.
2. I was given time to read it, or had it read to me, in the language I best understand.
3. I was given time to ask any questions I wanted to and found any answers given to me to be reasonable and satisfactory.
4. I believe I fully understand why the study is being conducted and what the intended outcomes will be.
5. I understand that there will be no immediate benefit to me, should I agree to participate, nor will I receive any payment; conversely, participation will not cost me anything but my time.
6. I understand that, even if I initially consent to take part in the study, I may subsequently withdraw at any time and would not be required to give any reasons; if that happened,

any data collected about me for the purposes of the study would immediately be destroyed, unless I give consent for it to be retained.

7. I have been given a range of contact details, listed below. If I require further information or become concerned about any aspect of this study, I am free to speak to any of these contacts.

Contact details:

Miss Lauren Tomes, Principal Investigator, telephone no. 0765888167, or by e-mail at lauren.tomes351@gmail.com.

Mrs Sonti Pilusa, Supervisor, on telephone no. 011 717 3715, or by e-mail at Sont.Pilusa@wits.ac.za.

If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Doctor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za.

The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za.

Name of Participant: _____

Date: _____

Place: _____

Signature or mark _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____

Appendix 3b: Participant Consent Form - Zulu

IFOMU LEMVUME YOMHLANGANISI

Isihloko Sephrojekthi: *Ukuba nakho Kwamathumbu, Isinye Nezinkinga Zocansi kanye nempumelelo yohlelo lwezempilo kwikhwalithi Yempilo nempilo yengqondo kubantu abane-SCI eManguzi.*

1. Nginikezwe Iphepha Lolwazi Lobambe iqhaza elichaza ubunjalo kanye izinqubo ezibandakanyekayo kulolu cwaningo, olunanyathiselwe lapha.
2. Nganikezwa isikhathi sokuyifunda, noma ukuba ngifundelwe yona, ngolimi engiluqonda kangcono.
3. Nganginikezwa isikhathi sokubuza noma yimiphi imibuzo engangiyifuna futhi ngathola noma yiziphi izimpendulo enganginikezwa zona ube onengqondo futhi anelise.
4. Ngikholwa ukuthi ngiqonda ngokugcwele ukuthi kungani ucwaningo lwenziwa nokuthi izoba yini imiphumela ehlosiwe.
5. Ngiyaqonda ukuthi ngeke ngibe khona inzuzo esheshayo, uma ngivuma ukuhlanganyela, futhi ngeke ngithole noma iyiphi inkokhelo; ngokuphambene, ukuhlanganyela ngeke kungibize lutho ngaphandle kwesikhathi sami.
6. Ngiyaqonda ukuthi, ngisho noma ekuqaleni ngivuma ukuba nengxenye ocwaningweni, ngemva kwalokho ngingahoxa noma nini futhi ngeke kudingeke ukuba nginikeze noma yiziphi izizathu; uma lokho kwenzeka,noma iyiphi idatha eqoqwe ngami ngezinjongo

zocwaningo izochithwa ngokushesha, ngaphandle uma nginikeza imvume yokuthi igcinwe.

7. Nginikezwe uhla lwemininingwane yokuxhumana, ebhalwe ngezansi. Uma ngidinga ulwazi olwengeziwe noma ngikhathazeka nganoma iyiphi ingxenye yalolu cwaningo, ngikhululekile ukukhuluma nanoma yimuphi walaba oxhumana nabo.

Imininingwane Yokuxhumana:

UNkosazana Lauren Tomes, uMphenyi Omkhulu, inombolo yocingo. 0765888167, noma nge-imeyili ku lauren.tomes351@gmail.com.

UNkk Sonti Pilusa, oyiSupervisor, enombolweni yocingo. 011 717 3715, noma nge-imeyili ku Sont.Pilusa@wits.ac.za.

Uma unokuthile okukukhathazayo ngendlela okwenziwa ngayo ucwaningo, sicela uthinte uSihlalo waleli Komidi onguDokotela Clement Penny okungathintwa ngaye, angathintwa kule nombolo yocingo 011 717 2301, noma nge-e-mail ku Clement.Penny@wits.ac.za

Izinombolo zocingo zikanobhala weKomidi zithi 011 717 2700/1234 kanye namakheli e-imeyili ngu Zanele.Ndlovu@wits.ac.za kanye no Rhulani.Mukansi@wits.ac.za

Igama Lombambi qhaza:_____

Usuku:_____

Indawo:_____

Isiginesha noma umaka:_____

Kufakazwe ngu:_____

Igama likafakazi:_____

Isiginesha:_____

Usuku:_____

Appendix 4a: Audio Recording Consent Form - English

CONSENT FORM FOR AUDIO RECORDING OF STUDY PARTICIPATION

Project Title: *Experience of Bowel, Bladder and Sexual Problems and the effectiveness of a health program on quality of Life and mental health in people with SCI in Manguzi*.

I hereby consent to audio recording of the interview.

I understand that:

- The recording will be stored in a secure location (a locked cupboard or password protected computer) with restricted access to the researcher and the research supervisor.
- The recording will be transcribed and any information that could identify me will be removed,
- The recordings will be erased within either (a) two (2) years of the publication of the research findings, or (b) six (6) years if no publications arise from this research.
- Anyone wishing to access this information in the future will first have to obtain the approval of the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg.
- Direct quotes from my interview, without any information that could identify me, may be cited in the research report or other write-ups of research.

Name of Participant: _____

Date: _____

Place: _____

Signature or mark: _____

Witnessed by:

Name of Witness: _____

Signature: _____

Date: _____

Appendix 4b: Audio Recording Consent Form - Zulu

IFOMU LEMVUME LOKUREKHODIWA KOMSINDO YOKUBAMBA IQHAZA EKUFUNDENI

Isihloko Sephrojekthi: *Ukuba nakho Kwamathumbu, Isinye Nezinkinga Zocansi kanye nempumelelo yohlelo lwezempilo kwikhwalithi Yempilo nempilo yengqondo kubantu abane-SCI eManguzi.*

Ngakho-ke ngivuma ukurekhodwa komsindo wenhlolokhono

Ngiyakuqonda ukuthi:

- Okurekhodiwe kuzogcinwa endaweni evikelekile (ekhabetheni elikhiyiwe noma ikhompuyutha evikelwe ngephasiwedi) enomkhawulo wokufinyelela kumcwaningi kanye nomphathi wocwaningo.
- Okurekhodiwe kuzobhalwa futhi noma yiluphi ulwazi olungangikhomba luzosuswa, . Okurekhodiwe kuzosulwa phakathi (a) neminyaka emibili (2) yokushicilelwa
- Okutholakele ocwaningweni, noma (b) iminyaka eyisithupha (6), uma kungekho okushicilelwe okuvela kulolu cwaningo
- Noma ngubani ofisa ukuthola lolu lwazi esikhathini esizayo kuzomele aqale athole imvume ye-Human Research Ethics Committee (Medical) yaseNyuvesi yaseWitwatersrand, eGoli.
- Izingcaphuno eziqondile ezivela kungxoxo yami, ngaphandle kwanoma yiluphi ulwazi olungangikhomba, zingacashunwa embikweni wocwaningo noma okunye ukubhalwa kocwaningo.

Igama Lombambi qhaza:_____

Usuku:_____

Indawo:_____

Isiginesha noma umaka: _____

Kufakazwe ngu:_____

Igama likafakazi: _____

Isiginesha: _____

Usuku:_____

Appendix 5a: Interview Guide - English

Good morning/afternoon, firstly thank you for your time. My name is Lauren Tomes, and I am a MSc student at the University of the Witwatersrand. Today joining me is my research assistant who will be assisting me in conducting the interviews in your home language, IsiZulu. I would really like to learn from you about your experiences on bowel, bladder, and sexual dysfunction and how it affects your mental health and QoL.

This interview should last about 1 hour and will be audio recorded as explained in the information sheet. I have specific questions I would like to ask, but please feel free to provide additional information. Please try to speak loudly, clearly, slowly so that your comments can all be audio recorded. Please also note that absolute anonymity cannot be guaranteed in the study; however, I will not be using your name when I am compiling the information for my report or submitting articles for any publication, instead you will receive a participant ID.

Before we start we are going to conduct a quick screening to identify whether you may need counseling if the need arises.

Screening questions	No	Yes	Follow up questions (if YES, ask questions)	Callers/ participants responses	Acute emotional distress or safety concern? (Y or N)
Are you experiencing a			1. Tell me what you are experiencing		

high level of stress or any emotional stress?			2. Is it getting in the way of things you need to do (work, family commitments, etc)? 3. Is it getting in the way of you taking care of yourself? 4. Have you been in the hospital recently for this problem?		
Are you currently having thoughts of harming yourself?			1. Tell me what thoughts you are having?		
Are you currently having thoughts of harming someone else?			1. Tell me what thoughts you are having?		
If you participated in the study			1. How might you be in danger?		

would you be in danger if anyone else found out?			2. What do you think would happen to you if you participated in the study?		

Do you have any other questions for me before we start?

Participants ID _____

Name of interviewer_____

Venue_____

Date_____

Theme 1: Life with a disability (SCI)

Can you tell me about yourself ….and your disability

Probe: Can you tell me about your experience living with spinal cord injury

Probe: How and when did the disability occur?

Probe: How did it change your life?

Theme 2: Bowel problems

Tell me about your bowel function and the problems that you may sometimes experience

Probe: Can you share your experience with bowel problems in your life

Probe: can you share with me how this problem affects your life?

Probe: How do you manage this problem?

Probe: what do you need to better manage bowel problems?

Theme 3: Bladder problems

Tell me about your bladder function? Is it similar your bowel function experience

Probe: Can you share your experience with bladder problems in your life

Probe: can you share with me how this problem affects your life?

Probe: How do you manage this problem?

Probe: what do you need to better manage bladder problems?

Theme 4: Sexual problems

Some people with SCI experience sexual problems. Can you share with me about the sexual problems you have experienced since SCI

Probe: can you share with me how sexual problems affect your life/relationship

Probe: How do you manage this problem?

Probe: what do you need to better manage sexual problems?

Theme 5: Suggestions

1. How can we improve care for these problems as healthcare professionals?

Thank you for opening and sharing with me. Please feel free to share anything else you may have forgot to mention.

Once again thank you for your time

Appendix 5b: Interview Guide - Zulu

Sawubona/ntambama, okokuqala ngiyabonga ngesikhathi sakho. Igama lami ngingu-Lauren Tomes, futhi ngingumfundi we-MSc eNyuvesi yaseWitwatersrand. Namuhla ongihlanganisayo umsizi wami wocwaningo ozongisiza ekuqhubeni inhlolokhono ngolimi lwenu, IsiZulu. Ngingathanda ngempela ukufunda kuwe mayelana nokuhlangenwe nakho kwakho ngamathumbu, esinyeni, nokungasebenzi kahle kwezocansi nokuthi kuyithinta kanjani impilo yakho yengqondo kanye ne-QoL.

Le nhlolokhono kufanele ithathe ihora eli-1 futhi izorekhodwa njengoba kuchaziwe eshidini lolwazi. Nginemibuzo ethile engingathanda ukuyibuza, kodwa ngicela ukhululeke ukunikeza ulwazi olwengeziwe. Sicela uzame ukukhuluma kakhulu, ngokucacile, kancane ukuze ukuphawula kwakho kuqoshwe wonke umsindo. Sicela futhi uqaphele ukuthi ukungaziwa ngokuphelele akukwazi ukuqinisekiswa ocwaningweni; kodwa-ke, ngeke ngisebenzise igama lakho lapho ngihlanganisa ulwazi lombiko wami noma ngihambisa izindatshana zanoma yikuphi ukushicilelwa, kunalokho uzothola i-ID yombambi qhaza.

Ngaphambi kokuthi siqale sizokwenza ukuhlolwa okusheshayo ukubona ukuthi ungadinga yini

Ukuhlola imibuzo	Cha	Yebo	Landela imibuzo (uma YEBO, buza imibuzo)	Abafonayo/ ababambiqhaza	Acute ngokomzwelo usizi noma ukukhathazeka? (Y noma N)
Ingabe ubhekene			1. Ngitshele ukuthi		

nezinga eliphezulu lokucindezeleka noma yikuphi ukucindezeleka ngokomzwelo?			ubhekene nani? 2. Ingabe kungukuphazamisa izinto okumele uzenze (umsembenzi, izibopho zomndeni, njll)? 3. Ingabe kuyakuvimba ukuthi uzinakekele? 4. Ingabe uke waba esibhedlela muva nje ngenxa yale nkinga?		
Ingabe njengamanje unemicabango yokuzilimaza?			1. Ngitshele ukuthi ucabangani?		
Ingabe manje unemicabango lokulimaza yomunye umuntu?			1. Ngitshele ukuthi ucabangani?		

Uma u ubambe iqhaza ocwaningweni ungaba sengozini uma omunye uthole?			3. Ungangena kanjani ingozi? 4. Ucabanga ukuthi kuzokwenzekani wena uma uhlanganyele ocwaningweni?		

ngabe unayo eminye imibuzo kimi ngaphambi kokuthi siqale?

I-ID yabahlanganyeli:_____

Igama lomxoxi:_____

Indawo:_____

Usuku:_____

Itimu 1: Impilo Enokukhubazeka (SCI)

Ungangitshela ngawe…nokukhubazeka kwakho

Uphenyo: Ungangitshela ngesipiliyoni sakho ngokuphila nokulimala komgogodla

Uphenyo: Kwenzeka kanjani futhi nini ukukhubazeka?

Uphenyo: Ishintshe kanjani impilo yakho?

Ngitshele ngokusebenza kwakho kwamathumbu kanye nezinkinga ongase ube nazo ngezinye izikhathi

Uphenyo: ungabelana nami ukuthi le nkinga iyithinta kanjani impilo yakho?

Uphenyo: Uyixazulula kanjani le nkinga?

Uphenyo: yini oyidingayo ukuze ulawule kangcono izinkinga zamathumbu?

Ingqikithi 2: Izinkinga zamathumbu

Uphenyo: Ungakwazi ukwabelana ngolwazi lwakho nezinkinga zamathumbu empilweni yakho?

Ingqikithi 3: Izinkinga zesinye

Ngitshele ngomsebenzi wakho wesinye? Ingabe kuyefana nakho kwakho kokusebenza kwamathumbu

Uphenyo: Ungakwazi ukwabelana ngolwazi lwakho nezinkinga zesinye empilweni yakho?

Uphenyo: ungabelana nami ukuthi le nkinga iyithinta kanjani impilo yakho?

Ingqikithi yesi-4: Izinkinga zocansi

Abanye abantu abane-SCI baba nezinkinga zocansi. Ungakwazi ukwabelana nami ngocansi izinkinga ohlangabezane nazo kusukela ku-SCI

Uphenyo: ungabelana nami ukuthi izinkinga zocansi ziyithinta kanjani impilo/ubudlelwano bakho

Uphenyo: Uyixazulula kanjani le nkinga?

Uphenyo: yini oyidingayo ukuze ulawule kangcono izinkinga zocansi?

Ingqikithi 5: Iziphakamiso

Singakuthuthukisa kanjani ukunakekelwa kwalezi zinkinga njengabasebenzi bezempilo?

Ngiyabonga ngokuvula nokwabelana nami. Sicela uzizwe ukhululekile ukwabelana nganoma yini enye ongase ube nayo ukhohlwe ukusho

Appendix 6: Demographic Questionnaire

Name /Identifier	
Gender	Male □ Female □
Date of birth	
Date of injury (SCI)	
Hospital duration after SCI	
Medical management	
SCI lesion level	
Type of lesion (paraplegia/quadriplegia)	
Secondary health conditions experienced (name them)	
Chronic conditions	
Medication	
State current rehabilitation care received	
Employment status	

Disability grant	Yes □ No □
Use of assistive device	Yes □ No □
State type of assistive device	
Member of NPO for people with disabilities?	Yes □ No □
If yes for above, which NPO	
Highest level of education	
Marital status	
Dependents (how many?)	
Do you have a Caregiver	Yes □ No □
Transport	Public □ Private □

Appendix 7a: WHOQoL- Bref Questionnaire English

WHO/MSA/MNH/PSF/97.4
English only
Distr.: Limited

WHOQOL-BREF

PROGRAMME ON MENTAL HEALTH
WORLD HEALTH ORGANIZATION
GENEVA

For office use only

	Equations for computing domain scores	Raw score	Transformed scores*	
Domain 1	(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18 ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐	=	**4-20**	**0-100**
Domain 2	Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26) ☐ + ☐ + ☐ + ☐ + ☐ + ☐	=		
Domain 3	Q20 + Q21 + Q22 ☐ + ☐ + ☐	=		
Domain 4	Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25 ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐	=		

* Please see Table 4 on page 10 of the manual, for converting raw scores to transformed scores.

I.D. number

ABOUT YOU

Before you begin we would like to ask you to answer a few general questions about yourself: by circling the correct answer or by filling in the space provided.

What is your **gender**? Male Female

What is you **date of birth**? _____ / _____ / _____
Day / Month / Year

What is the highest **education** you received?
None at all
Primary school
Secondary school
Tertiary

What is your **marital status**?
Single Separated
Married Divorced
Living as married Widowed

Are you currently **ill**? Yes No

If something is wrong with your health what do you think it is?_____illness/ problem

Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last two weeks.** For example, thinking about the last two weeks, a question might ask:

		Not at all	Not much	Moderately	A great deal	Completely
	Do you get the kind of support from others that you need?	1	2	3	4	5

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.

		Not at all	Not much	Moderately	A great deal	Completely
	Do you get the kind of support from others that you need?	1	2	3	4	5

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1(G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4(F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5(F4.1)	How much do you enjoy life?	1	2	3	4	5
6(F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7(F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
13 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither	Good	Very good

				poor nor good		
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
17 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18(F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
19 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
20(F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5
21(F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
22(F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23(F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24(F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
25(F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
26 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Did someone help you to fill out this form?.....

How long did it take to fill this form out?.....

Do you have any comments about the assessment?

.....

.....

THANK YOU FOR YOUR HELP

Appendix 7b: WHOQoL-Bref Questionnaire Translated into Zulu

MAYELANA NAWE

Ngaphambi kokuthi uqale sithanda ukukucela ukuthi uphendule imibuzo embalwa ejwayelekile ngawe: ngokuzungelezela impendulo efanele noma ngokugcwalisa isikhala esinikeziwe.

Buyini ubulili bakho? Owesifazane/ Owesilisa

Uthini usuku lwakho lokuzalwa? Usuku/ Unyaka/ Inyanga

Iyiphi imfundo ephakeme kakhulu oyitholile?

Lutho neze ☐

Isikole sebanga eliphansi ☐

Isikole samabanga aphezulu ☐

Siyini isimo sakho somshado?

Awushadile ☐

Ushadile ☐

Ukuphila njengomuntu oshadile ☐

Umfelokazi ☐

Behlukene Bahlukanisile ☐

Ingabe uyagula njengamanje? Yebo ☐

Cha ☐

Uma kukhona okungahambi kahle ngempilo yakho ucabanga ukuthi kuyini?

ukugula/ inkinga:

Iziyalezo:

Lokhu kuhlola kubuza ukuthi uzizwa kanjani ngezinga lempilo yakho, impilo, noma ezinye izici zempilo yakho. Sicela uphendule yonke imibuzo. Uma ungaqiniseki ngokuthi iyiphi impendulo

ongayinikeza embuzweni, sicela ukhethe leyo ebonakala ifaneleka kakhulu. Lokhu ngokuvamile kungaba impendulo yakho yokuqala.

Sicela ugcine engqondweni izindinganiso zakho, amathemba ubumnandi kanye nokukukhathazayo. Sicela ukuthi ucabange ngempilo yakho emasontweni amabili edlule. Isibonelo, uma ucabanga ngamaviki amabili adlule, umbuzo ungabuza:

Ingabe uyaluthola uhlobo lokusekelwa kwabanye oludingayo?	Akungalo neze 1	Hhayi kakhulu 2	Ngokulingene 3	Okuhle kakhulu 4	Ngokuphelele 5

Kufanele ubiyele inombolo elingana kangcono ukuthi kungakanani ukwesekwa okuthole kwabanye kule maviki amabili edlule. Ngakho-ke ungazungeza inombolo 4 uma uthla ukwesekwa okukhulu kwabanye ngale ndlela elandelayo

Ingabe uyaluthola uhlobo lokusekelwa kwabanye	Akungalo neze 1	Hhayi kakhulu 2	Ngokulingene 3	Okuhle kakhulu 4	Ngokuphelele 5

oludingayo?					

Ubuzokokelezela inombolo 1 um ungalutholi usizo obuludinga kwabanye emasontweni amabili edlule.

Sicela ufunde umbuzo ngamunye, uhlole imizwa yakho, bese uzungeza inombolo esikalini sombuzo ngamunye lokho kukunikeza impendulo engcono kakhulu kuwe.

Ungalilinganisa kanjani izinga lakho lempilo?	Impofu kakhulu 1	Impofu 2	Akuyona empofu noma enhle 3	Kuhle 4	Kuhle kakhulu 5

Waneliseke kangkanani ngempilo yakho?	Anganelisekile kakhulu	Anganelisekile	Nakanye wanelisekile noma onganelisekile	Ngenelisekile	Wanelisekile kakhulu

	1	2	3	4	5

Imibuzo elandelayo ibiza ukuthi uhlangabezane kangakanani nezinto ezithile emasontweni amabili edlule

	Luthi neze	Kancane	Inani elimphakathi	Kakhulu	Inani elibi kakhulu
Uzwa kangakanani ukuthi ubuhlungu bomzimba bukuvimbela ukuthi wenze lokho okwenzayo udinga ukwenza?	1	2	3	4	5
Kungakanani okudingayo noma yikuphi ukwelashwa ukuze	1	2	3	4	5

usebenze ekuphileni kwakho kwansuku zonke?					
Uyijabulela kangakanani impilo?	1	2	3	4	5
Ucabanga ukuthi ukuphila kwakho kunenjongo kangakanani?	1	2	3	4	5

	Lutho neze	Kancane	Inani elimaphakathi	Kakhulu	ngokwedlulele
Ukwazi kanjani ukugxilisa ingqondo	1	2	3	4	5
Uzizwa uphephe kangakanani	1	2	3	4	5

ekuphileni kwakho kwansuku zonke?					
Unempilo kangakanani emzimbeni wakho	1	2	3	4	5

Imbuzo elandelayo ibuza mayelana nokuthi uzizwe uphelele kangakanani noma ukwazile ukwenza izinto ezithile emasontweni amabili edlule

	Lutho neze	Kancane	Ngokulingene	Ikakhulukazi	Ngokuphelele
Ingabe unayo amandla anele for impilo yansuku	1	2	3	4	5
Ungakwazi yini ukwamukela umzimba wakho ukubukeka?	1	2	3	4	5
Unayo imali eyanele	1	2	3	4	5

ukuhlangabezana neyakho izidingo?					
Ukutholakala kwakho ulwazi okudingayo ekuphileni kwakho kwansuku zonke?	1	2	3	4	5
Ngabe unalo kangkanani ithuba lezinto zokungcebeleka ?	1	2	3	4	5

	Impofu kakhulu	Impofu	Nakanye	Kuhle	Kuhle kakhulu
Waneliseke kangakanani ngokulala kwakho?	1	2	3	4	5
Waneliseke	1	2	3	4	5

kangakanani ngekhono lakho ukwenza imisebenzi yakho yansuku zonke?					
Waneliseke kangakanani ngomthamo wakho ngomsebenzi ?	1	2	3	4	5
Waneliseke kangakanani ngawe?	1	2	3	4	5
Waneliseke kangakanani ngeyakho ubudlelwano bomuntu siqu?	1	2	3	4	5
Waneliseke kangakanani ngempilo yakho	1	2	3	4	5

yocansi?					
Waneliseke kangakanani ngosekelo oluthola kubangani bakho?	1	2	3	4	5
Waneliseke kangakanani ngezimo zendawo ohlala kuyo?	1	2	3	4	5
Waneliseke kangakanani ngofinyelela kwakho ezinsizeni zezempilo?	1	2	3	4	5
Waneliseke kangakanani ngezokuthutha zakho?	1	2	3	4	5

Umbuzo olandelayo ubhekisa ekutheni uzizwe kangaki noma wehlelwa ezithile emasontweni amabili edlule

	Ungalokothi	Akuvamile	Kaningi	Ngokujwayelekile	Njalo
Kukangaki uba nemizwa engemihle ezifana blue mood, ukuphelelwa ithemba, ukukhathazeka, ukucindezeleka ?	1	2	3	4	5

Ingabe ukhona okusize ukugcwalisa leli fomu?

Kuthathe isikhathi esingakanani ukugcwalisa leli fomu?

Ingabe unakho ukuphawula mayelana nokuhlola?

NGIYABONGA NGOSIZO LWAKHO

Appendix 8a: SF-12 Questionnaire English

SF12 HEALTH SURVEY

ID NUMBER: | | | | | | | | |

FORM CODE: **SFH**
VERSION: **3.0** 11/07/2017

Event: _____

0a) Date of Collection ☐☐ / ☐☐ / ☐☐☐☐ 0b) Staff Code ☐☐☐

Instructions: *This form should be completed during the clinic visit. Please read each question carefully.*

The first question is about your health now. Please try to answer as accurately as you can.

1) In general, would you say your health is...
- ☐ Excellent$_1$
- ☐ Very good$_2$
- ☐ Good$_3$
- ☐ Fair$_4$
- ☐ Poor$_5$

Now, please think about the activities that you might do during a typical day. As you read each item, please select whether your health now limits you a lot, limits you a little, or does not limit you at all when doing these activities.

2a) …moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf. Does your health now limit you a lot, limit you a little, or not limit you at all?
- ☐ Yes, Limited a lot$_1$
- ☐ Yes, Limited a little$_2$
- ☐ No, Not at all limited$_3$

2b) …climbing several flights of stairs. Does your health now limit you a lot, limit you a little, or not limit you at all?
- ☐ Yes, Limited a lot$_1$
- ☐ Yes, Limited a little$_2$
- ☐ No, Not at all limited$_3$

The following two questions ask you about your physical health and your daily activities.

3a) During the past four weeks, how much of the time have you accomplished less than you would like as a result of your physical health?
- ☐ All of the time$_1$
- ☐ Most of the time$_2$
- ☐ Some of the time$_3$
- ☐ A little of the time$_4$
- ☐ None of the time$_5$

3b) During the past four weeks, how much of the time were you limited in the kind of work or other regular daily activities you do as a result of your physical health?

- ☐ All of the time$_1$
- ☐ Most of the time$_2$
- ☐ Some of the time$_3$
- ☐ A little of the time$_4$
- ☐ None of the time$_5$

The following two questions ask you about your emotions and your daily activities.

4a) During the past four weeks, how much of the time have you accomplished less than you would like as a result of any emotional problems, such as feeling depressed or anxious?

- ☐ All of the time$_1$
- ☐ Most of the time$_2$
- ☐ Some of the time$_3$
- ☐ A little of the time$_4$
- ☐ None of the time$_5$

4b) During the past four weeks, how much of the time were you limited in the kind of work or other regular daily activities you do as a result of any emotional problems, such as feeling depressed or anxious?

- ☐ All of the time$_1$
- ☐ Most of the time$_2$
- ☐ Some of the time$_3$
- ☐ A little of the time$_4$
- ☐ None of the time$_5$

5) During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- ☐ Not at all$_1$
- ☐ A little bit$_2$
- ☐ Moderately$_3$
- ☐ Quite a bit$_4$
- ☐ Extremely$_5$

The next four questions are about how you feel and how things have been with you during the past 4 weeks. As you read each statement, please select the one answer that comes closest to the way you have been feeling; is it all of the time, most of the time, some of the time, a little of the time, or none of the time?

6a) How much of the time during the past 4 weeks…have you felt calm and peaceful?

- ☐ All of the time$_1$
- ☐ Most of the time$_2$
- ☐ Some of the time$_3$
- ☐ A little of the time$_4$
- ☐ None of the time$_5$

6b) How much of the time during the past 4 weeks…did you have a lot of energy?

- ☐ All of the time$_1$
- ☐ Most of the time$_2$
- ☐ Some of the time$_3$
- ☐ A little of the time$_4$
- ☐ None of the time$_5$

6c) How much of the time during the past 4 weeks…have you felt downhearted and depressed?

- ☐ All of the time$_1$
- ☐ Most of the time$_2$
- ☐ Some of the time$_3$
- ☐ A little of the time$_4$
- ☐ None of the time$_5$

7) How much of the time during the past 4 weeks…has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- ☐ All of the time$_1$
- ☐ Most of the time$_2$
- ☐ Some of the time$_3$
- ☐ A little of the time$_4$
- ☐ None of the time$_5$

END OF FORM

Appendix 8b: SF-12 Questionnaire translated into Zulu

Instruction/Umlayezo: Leli fomu kufanele *ligcwaliswe ngesikhathi kuvakashelwe emtholampilo. Uyacelwa ukuthi ufunde umbuzo ngamunye ngokucophelela*

Umbuzo wokuqala umayelana nempilo yakho njengamanje. Uyacelwa ukuthi uzame ukuwuphendula ngokuqondile.

1) Ngokujwayelekile, kungaba impilo yakho

- Ikahle kakhulu
- Ikahle ngokujabulisayo
- Ikahle
- Ikahle ngokulingene
- Kubi

Manje, sicela ucabange ngezinto ongazenza osukwini. Njengoba ufunda into ngayinye, sicela ukhethe ukuthi ingabe impilo yakho manje ikuvimbela kakhulu, ikuvimbela kancane okukanye ayikuvimbeli uma wenza imisebenzi.

2a) Imisebenzi emaphakathi, njengokugudluza itafula, umshini wokuhlanza, ibowling okukanye ukudlala igalofu. Ingabe impilo yakho ikuvimbela kakhulu, ikuvimbela kancane, okukanye ayikuvimbeli nakancane.

- Yebo, ingivimbela kakhulu
- Yebo, ingivimbela kancane
- Cha, ayingivimbeli nakancane

2b) Ukugibela izi tebhisi ezimbalwa. Ingabe impilo yakho ikuvimbela kakhulu, ikuvimbela kancane, okukanye ayikuvimbeli nakancane.

- Yebo, ingivimbela kakhulu
- Yebo, ingivimbela kancane
- Cha, ayingivimbeli nakancane

Lemibuzo emibili elandelayo ikubuza ngempilo ngokomzimba ezintweni ozenza ngosuku

3a) Emavikini amane edlule, singakanani isikhathi okufezile kancane kunalendlela obukade ufisa ngayo ngenxa yempilo ngokomzimba.

- Ngasosonke isikhatio
- Ngezikhathi eziningi
- Ngezinye izikhathi
- Ngesikhashana
- Akunasikhathi

3b) Emavikini amane edlule, singakanani isikhathi ovimbeleke ngaso ngokomsebenzi okukanye imisebenzi yosuku oyenzayo ngenxa yempilo ngokomzimba.

- Ngasosonke isikhatio
- Ngezikhathi eziningi
- Ngezinye izikhathi
- Ngesikhashana
- Akunasikhathi

Lemibuzo emibili elandelayo ikubuza mayelana nemizwa yakho kanye nemisebenzi yakho yosuku.

4a) Emavikini amane edlule, singakanani isikhathi okufezile kancane kunalendlela obukade ufisa ngayo ngenxa yenkinga yemizwa, njengokuthi uzizwe udangele okukanye ukukhathazeka.

- Ngasosonke isikhatio
- Ngezikhathi eziningi
- Ngezinye izikhathi
- Ngesikhashana
- Akunasikhathi

4b) Emavikini amane edlule, singakanani isikhathi lapho ovimbeleke ukwenza umsebenzi othize okukanye izinto ozenza ngosuku ngenxa yenkinga yemizwa, njengokuthi uzizwe udangele okukanye ukukhathazeka.

5) Emavikini amane edlule, bungakanani ubuhlungu obuphazamise umsebenzi wakho ojwayelekile (okuhlanganisa ukusebenza ngaphandle kwekhaya nomsebenzi wasendlini.

- Akukho nakancane
- Kancane
- Kuphakathi
- Kancane kancane
- Ngokwedlulele

Lemibuzo emine elandelayo imayelana nokuthi uzizwa kanjani okukanye zibenjani emuva kwalamaviki amane. Njengoba ufunda isitatimende ngasinye, ucelwa ukuthi ukhethe impendulo eyodwa esondelene nendlela obuzizwa ngayo; Ngasosonke isikhathi, Ngezikhathi eziningi, Ngezinye izikhathi, Ngesikhashana, Akunasikhathi

6a) Singakanani isikhathi kulamaviki amane adlule lapho uzizwe khona uzothile futhi unokuthula.

- Ngasosonke isikhatio
- Ngezikhathi eziningi
- Ngezinye izikhathi
- Ngesikhashana
- Akunasikhathi

6b) Singakanani isikhathi kulamaviki amane adlule lapho uzizwe khona unomdlandla omningi.

- Ngasosonke isikhatio
- Ngezikhathi eziningi
- Ngezinye izikhathi
- Ngesikhashana
- Akunasikhathi

6c) Singakanani isikhathi kulamaviki amane adlule lapho uzizwe uphuke umoya futhi udangele

- Ngasosonke isikhatio
- Ngezikhathi eziningi
- Ngezinye izikhathi
- Ngesikhashana
- Akunasikhathi

7) Singakanani isikhathi kulamaviki amane adlule lapho impilo yakho ngokomzimba okukanye izinkinga yomuzwa ekuphazamisa emisebenzini yomphakathi (njengokuvakashela abangani, izihlobo nokunye)

- Ngasosonke isikhatio
- Ngezikhathi eziningi

- Ngezinye izikhathi
- Ngesikhashana
- Akunasikhathi

Liyaphela ifomu

Appendix 9: Health Intervention Information Guideline – tailored to the needs

Bowel Function After Spinal Cord Injury

March 2015 | www.msktc.org/sci/factsheets | SCI Fact Sheet

This fact sheet tells you about why a bowel program can improve your quality of life.

What you need to know

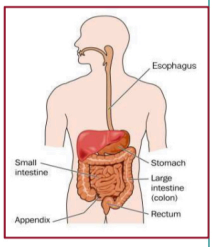
A spinal cord injury can lead to bowel problems:

- You may have problems moving waste through your colon (or large intestine).
- You may pass a stool when you don't want to, or a stool may be hard to pass.
- These problems can cause pain in your abdomen.
- When eating, you may feel full sooner than normal, or you may eat less than you usually do.
- Bowel problems can contribute to depression or anxiety. You may feel overly concerned about not being able to control bowel movements in public. You may not want to do things outside of your home.

A bowel program can help you to control bowel movements. Following a bowel program can help you to avoid other problems and perhaps bowel surgery.

Understanding your body

Your stomach and small intestine pull nutrients from the food you eat. Nutrients keep you strong and give you energy. The rest of the food becomes waste that your body doesn't need. Waste forms into a stool in your colon and rectum and leaves your body through the anus. The process of passing a stool through and out of your body is known as a "bowel movement." If you have a spinal cord injury, this process may be tough for you. For example, you may have a difficult time passing stools. This is called "constipation." Or you may not be able to control when you pass a stool. This is called "stool incontinence."



Spinal cord injuries may cause tightness (spasticity) or looseness (flaccidity) in the muscles of the rectum, sphincters, and pelvic floor. The degree of tightness or looseness may be related to the severity or completeness and level of your injury. If your injury is above level T11/T12, then the muscles of your sphincters and pelvic floor may be tight, which leads to constipation. If your injury is level T11/T12 or lower, then these muscles may be loose, which leads to stool incontinence. People with incomplete spinal cord injuries tend to have more muscle strength and sensation and therefore have fewer bowel problems than people with complete injuries.

What is a bowel program?

A bowel program is a plan to retrain your body to have regular bowel movements. A doctor or nurse designs a bowel program specifically for you. Your health, bowel and personal history, physical examination are an important part of this review:

- The level and completeness of your spinal cord injury
- Description and pattern of bowel problems
- Past and present medical problems
- Intake of food and drink
- Physical activities
- Need for or availability of resources
- Home environment
- Lifestyle
- Preferences
- Gastrointestinal tests

The goals of a bowel program are:

- Passing a stool every day or every other day
- Preventing unplanned bowel movements
- Emptying your bowel around the same time of day (e.g., morning, afternoon, or evening)
- Passing medium or large stool (about 2 cups) every time you have a bowel movement
- Emptying all or most of your rectum each day
- Having stools that are soft, formed, and bulky
- Emptying your bowel completely within 30 minutes (or 60 minutes, at most) after eating

What is involved in a bowel program?

A bowel program includes four parts: timing, diet (including food and fluids), medicines, and techniques to help with bowel movements. The program isn't the same for everybody, because each person has different needs and responds differently to each part of the program.

Timing

A bowel program is best when done every day or every other day. A program involves:

- Eating a good diet and drinking plenty of fluids
- Using bowel medicines, as recommended by your doctor
- Practicing techniques that activate the reflex to empty your rectum
- Using methods to clean out stools

Diet and fluids

Eating a good diet and drinking plenty of fluids are important to bowel health:

- Natural fiber from fruits and vegetables increases the bulk of stool, making it easier to move through the colon. Doctors recommend 38 grams of fiber per day for men and 25 grams per day for women.
- When eating a diet high in fiber, you should drink plenty of fluids. Water is best. You may get constipated if you don't drink enough fluids. You should drink at least 2 or 3 quarts of fluids every day, unless told otherwise by your doctor.
- You should limit your intake of liquids with caffeine (e.g., coffee, tea, or energy drinks). These drinks actually remove fluids from your body.

Medicines

Your doctor may have you take one or more medicines, either orally or rectally:

- Stool softeners make stools soft and easy to move.
- Stimulant laxatives stimulate the colon to move stools.
- Bulking laxatives add shape and form to stools and prevent diarrhea (watery stools).
- Rectal laxatives help with rectal movement and emptying.

Some medicines may cause constipation. They may be ones that you're taking already to reduce pain or muscle spasms or to treat depression. You may benefit from minimizing your use of these medicines under the supervision of your physician:

- Medicines to reduce pain, such as hydrocodone, oxycodone, morphine, fentanyl, gabapentin, pregabalin, or carbamazepine
- Medicines to treat bladder spasms but slow down intestinal motility, such as oxybutynin or tolerodine
- Medicines to stop muscle spasms all over the body, such as lioresal, tizanidine, or diazepam
- Medicines to treat depression. such as cymbalta. sertraline. or citalopram

Techniques

You can do one or more techniques to help you have a bowel movement and empty your rectum. You can do these at home or with help from a caregiver or nursing aid.

- **Digital rectal stimulation:** Move your fingertip in a small, gentle, circular motion around the rectum/anus. This motion stimulates reflex of the rectum/anus. Be sure to cut your fingernails short to avoid trauma. Perform this technique for 20 seconds and repeat it every 5–10 minutes until the bowel program is completed and the rectum is empty.
- **Digital removal of stool:** Use your finger to remove stool from the rectum. This will speed up your ability to empty the rectum.
- **Enema:** Use a device to flush warm water into your rectum, which will help to empty it of stool. Examples of devices include the catheter enema or cone enema. If these simple enemas do not work, other home stool evacuation devices like the Peristeen enema and PIE (Pulsed Irrigation Evacuation) systems which have been approved by the U.S. Food and Drug Administration may help.

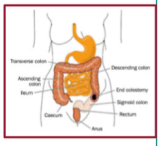
What if I can't do a bowel program or it doesn't work?

A serious injury may keep some people from carrying out a bowel program. For others, the program just may not work. Every person is different. Surgery may be a good option in a few cases, for example:

- If you can't achieve regular, complete bowel movements, which can lead to recurrent severe constipation (associated with frequent hospital admissions for stool loading and obstruction; chronic abdominal pain; prolonged [>1 hour], difficult bowel programs; or severe autonomic dysreflexia[1]).
- If you have frequent stool incontinence (associated with pressure sores) or lack caregiver support, both of which may contribute to a poor quality of life and confinement in the home.

Other options include two kinds of surgery.

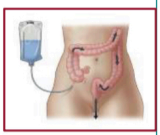
Colostomy



Surgeons attach the colon to the abdominal wall through a hole called a "stoma" (or opening). A bag is attached to the stoma. Stools pass into the bag instead of through the rectum. You or a caregiver empty and change the bag easily and regularly. (The end of colostomy is shown in the image.)

Most people who have the colostomy choose to have it permanently. The colostomy promotes good bowel movements and is easy to manage by yourself or by a caregiver. The procedure prevents stool incontinence and unplanned bowel movements. It also decreases mental stress so you can do more activities outside the home with family and friends.

Antegrade Continence Enema



Surgeons open the abdominal wall to create a tract to either the first part of the colon (ascending colon) or the last part of the colon (descending colon/sigmoid) (See figure). You or a caregiver place an enema catheter through the stoma daily to flush the stool out of the colon with 500–1000mL of tap water. This process usually lasts from 30 to 60 minutes. Cleansing the colon daily and regularly prevents unplanned *bowel* movements and stool incontinence.

[1] Autonomic dysreflexia (pronounced aw-to-nom-ik dis-ree-FLEKS-ee-ah) is a serious condition in which dangerously high blood pressure is associated with a drop in heart rate in people with spinal cord injury at levels T6 and above. It may cause heavy sweating, flushing, headaches, and blurry vision. If left untreated, the condition may lead to stroke, bleeding in the eyes, swelling of the heart or lungs, and other severe health problems.

Why is maintaining bowel function so important?

Worsening and untreated bowel function can lead to other health problems:

- Partial paralysis of the stomach
- Chronic heartburn
- Gas pain
- Stomach or intestinal ulcers
- Hemorrhoids
- Abdominal discomfort, pain, or distension
- Nausea
- Bloating or fullness
- Change in weight (related to a poor diet or a decrease in appetite)
- Autonomic dysreflexia - This is a serious condition where a dangerous elevation in blood pressure is associated with a drop in heart rate in people with spinal cord injury at levels T6 and above. It may cause heavy sweating, flushing, headaches, and blurry vision. If left untreated, it may lead to stroke, bleeding in the eyes, swelling of the heart or lungs, and other severe health problems.
- Worsening pain and/or spasticity
- Decreased sense of well-being

These health problems can reduce your quality of life. But you may be able to avoid these problems by following a bowel program every day. Your doctor or nurse can help you and will check with you to see how you're doing. Ask questions, and let your health care professional know about any problems you're having.

Authorship

Bowel Function Problems After Spinal Cord Injury was developed by Gianna M. Rodriguez, M.D., in collaboration with the Model Systems Knowledge Translation Center

The Spinal Cord Injury Model System is sponsored by the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education. (See http://www.msktc.org/sci/model-system-centers for more information).

Bladder Management Options Following Spinal Cord Injury

September 2015 www.msktc.org/sci/factsheets SCI Fact Sheet

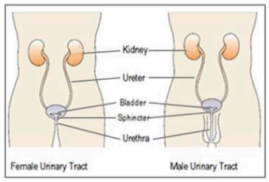
This fact sheet tells you about some of the more common methods to manage your bladder if it is not working correctly following your spinal cord injury

What you need to know

- Your spinal cord injury (SCI) might limit your ability to control your urine. You might not be able to stop urine from flowing, or you might not be able to release it.
- Uncontrolled urination or inability to empty your bladder can have a negative effect on your quality of life and cause bladder and kidney infections and other problems.
- Appropriate bladder management can help keep your bladder and kidneys healthy.
- Each type of bladder management option has pros and cons.
- Your doctor can help you choose the bladder management option that best meets your needs and lifestyle, and keeps your bladder and kidneys healthy.

Understanding your body

- The kidneys remove waste from your body through your blood stream. This waste becomes urine.
- The urine passes down the ureters (pronounced YOU-ret-erz) into the bladder. The sphincter (pronounced SFINK-ter) muscle at the end of the bladder acts like a valve that you can tighten to keep urine from leaving your body. (When you urinate, your sphincter normally relaxes and your bladder squeezes to push the urine out of your bladder).



- Urine passes from the bladder through the urethra (pronounced yur-EETH-rah) out of your body. In women, the urethra is right above the vagina. In men, the urethra is in the penis. The inability to control the release of urine is called urinary incontinence (pronounced in-KAHN-ten-ans). The inability to release urine from your bladder when it is full is called urinary retention.

What does my spinal cord have to do with my bladder?

- Your brain sends and receives signals through your spinal cord. At the lowest part of your spinal cord (see **MSKTC factsheet entitled *Understanding SCI Part 1*** ***http://www.msktc.org/lib/docs/Factsheets/SCI_Understand_Spin_Crd_Inj_Prt1.pdf***) is an area called the sacral micturition (pronounced SAY-krul mich-ter-ishun) center that has nerves attached to it that go to and from the bladder. These nerves help to signal the brain when the bladder needs to be emptied. They also control the sphincter.
- For example, if you need to hold your urine until a convenient time to empty your bladder, your brain will signal the bladder not to squeeze and the sphincter to tighten so that you can wait. When it is time to release your urine, signals from your brain will then send signals down your spinal cord to squeeze the bladder and relax the sphincter. If an SCI has damaged the spinal cord, the signals from the brain to the bladder do not work correctly and you might not be able to control your urine. You might not be able to stop urine from flowing (urinary incontinence), or you might not be able to release it (urinary retention).

The Spinal Cord Injury Model System is sponsored by the National Institute of Disability, Independent Living, and Rehabilitation Research, U.S. Department of Health and Human Services' Administration for Community Living. Opinions expressed in this fact sheet are not necessarily those of the granting agency. (See **http://www.msktc.org/sci/model-system-centers** for more information).

What bladder problems can an SCI cause?

An SCI can cause two types of bladder problems. One set of problems occurs immediately after injury, and the other may begin later on after your injury (long term) when you are out of spinal shock (see below)

Immediately after SCI:

- You might experience spinal shock, when signals from the brain can't get to any or most parts of the body below the spinal cord injury.
- Spinal shock in general usually lasts for up to a few days, but for the bladder it can last several months or longer.
- Your bladder does not squeeze when you are in the period of spinal shock.

After your bladder is out of spinal shock:

- Signals to and from your brain may still be blocked by the SCI.
- Your sacral micturition center is an area of the spinal cord at the base of the spine. This is the area of the spinal cord that controls your bladder and sphincter.
- After spinal shock, your sacral micturition center it might start sending signals on its own to tell the bladder to squeeze. In addition, signals that would normally come down from your brain to keep your sacral micturition center from sending signals to make your bladder squeeze are blocked by your SCI. Therefore your bladder begins to squeeze and possibly cause you to also urinate without control (urinary incontinence). This is known as a "neurogenic overactive bladder."
- Your sphincter might tighten or relax on its own, starting and stopping your urine stream without your control.
- Your bladder might try to squeeze but the sphincter might tighten at the same time, making you unable to urinate and causing a high-pressure buildup in the bladder. This is known as detrusor (bladder) sphincter dyssynergia (pronounced dis-IN-ergh-IAH). This can stretch your bladder beyond what is healthy and can cause bladder infections.
- High pressures in your bladder can also prevent urine from draining from your kidneys to your bladder and can cause kidney infections, kidney stones, and even kidney damage.
- Another problem that can occur in those with SCI at T6 and above is autonomic dysreflexia. This can happen when something causes pain or discomfort to your body even though you may not feel it. The two most common causes are bladder distention (and bladder contractions) and constipation. Autonomic dysreflexia causes a sudden severe elevation in blood pressure which has the potential of being dangerous. Autonomic dysreflexia may or may not (silent autonomic dysreflexia) cause other symptoms such as headache, flushing, and/or goose bumps. It will not get better until the cause of the autonomic dysreflexia is taken care of, such as emptying the bladder. (See the reference below for more details on acute autonomic dysreflexia.)
- Over time there are also risks of having other problems such as bladder or kidney infections and a slight risk of developing bladder cancer, bladder or kidney stones, or kidney damage.

Does the level of injury on my spine affect what problems I experience?

- Yes, however everyone's bladder and sphincter act a little differently because the amount of nerve injury is a little different for each person even if you have the same level of injury as someone else.
- Keeping that in mind, the major areas to consider are:
  1. At or below the sacral micturition center
  2. Above the sacral micturition center.

At or Below the Sacral Micturition Center:

- If the SCI damaged the spinal cord at or near the base of your spine, the sacral micturition center might be damaged.
- When this center is damaged, signals can't be sent to the bladder to tell the bladder to squeeze (neurogenic underactive bladder).
- It the damage is below your sacral micturition center then even though signals are sent towards the bladder, the nerves to the bladder are damaged so the signals do not reach the bladder and your bladder will not squeeze.
- Your bladder will then become very full (over distended).
- If you have a weak urinary sphincter, urine will probably overflow from your bladder without your control (urinary incontinence).
- If you have a strong urinary sphincter, urine may not be able to be released leading to a possible increase in bladder pressure and possible back-up of urine in your kidneys.

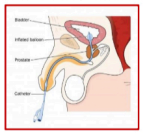
Above the Sacral Micturition Center:

- The sacral micturition center sends signals to your bladder causing it to squeeze. Your spinal cord injury also blocks signals coming down from the brain which are telling the bladder when and when not to squeeze, causing you to have an overactive bladder. (See above section.)
- Signals also don't usually get to your urinary sphincter to tell it to relax when your bladder is squeezing (detrusor sphincter dyssynergia). (See above section.)
- If your injury is at T6 or above you may get autonomic dysreflexia from your overactive bladder and detrusor sphincter dyssynergia.

How can I know if my bladder and sphincter are working correctly?

Doctors can do a urodynamics (pronounced yur-oh-di-NAM-iks) test to see how well your bladder and sphincter are working:

- A catheter (a small tube) goes up through your urethra into the bladder.
- Your bladder is slowly filled with fluid.
- Doctors then measure how your bladder and sphincter respond to the fluid in the bladder.
- The test can help inform which bladder management option is best for you.



What is bladder management?

Bladder management is an ongoing set of treatments and practices that help keep your bladder and kidneys healthy and free from infection and other problems.

- Bladder management cannot fix or solve the problems caused by your SCI, but it can help you manage them to improve your health and quality of life. With appropriate management you can prevent incontinence and damage to the kidneys.
- You can work with your doctor to choose which bladder management option fits into your lifestyle and maintains bladder and kidney health.

What are some types of bladder management?

There are many types bladder management following SCI, each with various advantages and disadvantages. Several of the more common types of bladder management are listed below. It is important to speak with your health care provider to determine which option is best for you.

If you continue to have significant problems affecting your kidneys or bladder or your lifestyle despite non-surgical bladder management options, your doctor might in rare cases suggest a surgical option such as a urinary diversion. For more information on surgical management, see ***MSKTC factsheet entitled Surgical Alternatives for Bladder Management Following SCI*** **http://www.msktc.org/sci/factsheets/bladdersurgery**. This fact sheet will focus on some of the more common non-surgical options of bladder management.

Intermittent Catheterization (pronounced kath-et-er-iz-AY-shun)

This option is used for draining your bladder without keeping a catheter in your bladder all the time.

- You (or someone else) insert a catheter into your bladder to keep your bladder from getting too full.
  - To do this, pass the catheter up your urethra into the bladder. The urine drains out the other end.
  - When done, remove the catheter and return to normal activities.
  - Do this as often as needed (usually 4-6 times per day). The goal is to keep your catheterization volumes less than 500 ml. (about 17 fl oz) so you may have to catheterize more or less often depending on how much you drink.
  - You will often need medication or injections (such as Botox) to keep your bladder quiet in order to prevent leaking and high pressures in your bladder.

- This option might NOT be for you if:
  - You are unable to catheterize yourself (or don't have someone to help you).
  - Your bladder is very small (so you would have to catheterize your bladder very frequently).
  - Your bladder is overactive (even with treatment; so you may have high bladder pressures or incontinence).
  - Your sphincter is overactive (will not relax easily; so the catheter will not pass easily into your bladder).
  - Your sphincter is underactive (will not tighten; so you will have frequent urinary incontinence).
  - You have a false passage in your urethra (so the catheter may get caught in the false passage).
  - You drink a lot of fluid (more than 2 -21/2 quarts or 2 liters) every day so you would need to catheterize very frequently).
  - You have a lot of pain when inserting or removing the catheter.
- You can use different types of catheters. Your doctor can help you decide which type of catheter is best for you. For example, the catheter might:
  - Have a slight curve at the tip. This is known as a Coudé (pronounced ku-DAY) catheter.
  - Have a bag attached at the end to catch the urine.
  - Be covered with lubricant to help it slide through your urethra.

Advantages:

- Intermittent catheterization simulates normal bladder filling which helps to maintain your normal bladder size
- You will not wear an internal or external catheter and leg bag all the time.

Disadvantages:

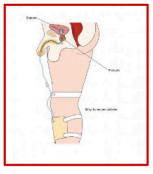
- You need to keep track of your fluid intake so that your bladder doesn't fill up too soon and get overstretched, especially while you are sleeping.
- You need to partially undress each time you use a catheter.
- You might find removing and inserting a catheter uncomfortable.
- If you are a woman, you might have trouble finding and passing your catheter into your urethra. You might cause some irritation or bleeding when passing a catheter into your bladder, especially if you are a man and have a very spastic urinary sphincter that tightens when you try to remove the catheter.
- You may need to take medication to keep your bladder from being overactive and causing urinary leakage.

Indwelling Catheterization

This option is used for ongoing protection from urinary retention or urinary incontinence. Indwelling catheterization uses a catheter and a urine collection bag that stays in place all the time. The catheter has a balloon at the tip of the catheter which sits in your bladder. Once the catheter is in your bladder, the balloon can be inflated to keep the catheter from falling out or deflating when it's time to change the catheter.

There are two types of indwelling catheters: urethral catheters and suprapubic (pronounced soo-prah-PEW Bik) catheters. Most urethral catheters that are kept in place by filling up a balloon. People might call your indwelling catheter a Foley catheter.

Type 1: Urethral Catheters



A urethral catheter is inserted through your urethra, by yourself, by a physician, nurse or a trained family member using a similar technique as intermittent catheterization. However, instead of removing the catheter when your bladder is empty, the indwelling catheter stays in your bladder and is held in place in your bladder by a small balloon at the end. A small tube connects the other end of the catheter into a collection bag. It is not a good idea to plug your catheter, especially if you do not have good sensation in your bladder. If your bladder fills up and gets over distended, it can cause serious problems such as a bladder or kidney infections or autonomic dysreflexia (if your injury is at T6 and above).

There are several types of collection bags:

- Smaller bags can be strapped to your leg so that you can move freely.
- Some larger bags don't have to be drained as often and are used when you are sleeping (called night bags).

- A modified bag can be strapped around your waist (called a belly bag) instead of your leg.

A collection bag must be emptied frequently:

- A collection bag must be emptied several times a day to keep it from getting too full. It is best to try to empty the bag when it gets about one half full.
- If the bag gets too full, pressure may build up in the bag and keep the urine from flowing down the tube. Instead, the urine will back up. This could cause your bladder to become over stretched and cause problems such as bleeding, bladder infection, or autonomic dysreflexia.

A urethral catheter stays in place all the time. About once a month, the catheter is removed and a new one is put in place. This may be done sooner if the catheter gets blocked from bladder stones or if there are other problems with the catheter's drainage.

Advantages

- You do not need to worry about inserting and removing the catheter into your bladder several times a day.
- You do not need to limit the amount of liquid you drink.
- You do not need to undress to use the catheter.

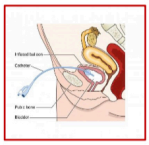
Disadvantages

- About 3 out of 10 people who use a urethral catheter get bladder stones, which are small hardened pieces that collect and can block your catheter and cause your bladder to get overstretched. This can cause leaking around the catheter, pain, a urinary tract infection, hematuria (blood in the urine), or autonomic dysreflexia.
- You might have discomfort or pain from the catheter, especially when inserting or replacing it.
- You might be uncomfortable wearing a urine collection bag and worry about it leaking.
- It can be difficult to keep the area around the catheter clean, especially for women.
- A constantly empty bladder can reduce the size of your bladder, making it less able to hold more urine.
- You may need to take medication to keep your bladder from being overactive and causing urinary leakage.
- There can be sexuality issues due to having a catheter in the urethra.
- There may be a slight increase in bladder infections with urethral catheters but not suprapubic catheters compared to other types of management.

Type 2: Indwelling Suprapubic Catheter

In order to insert an indwelling suprapubic catheter, a doctor first needs to make a small incision below the beltline This is done under an anesthetic. He or she then inserts the catheter through the incision into the bladder. Urine drains out from the catheter and is then stored in a collection bag on the outside of your body. The collection bag is drained as needed, to keep the bag from getting overfilled. The catheter is changed on a monthly basis just like a urethral catheter.

After the catheter has been put in by a doctor, the incision heals and there is a small hole so that the old catheter can be removed and a new catheter can be inserted. It is important to measure the distance that the catheter is in your bladder by marking the catheter at the skin level before removing it and then putting the new catheter in the same distance in. As long as a catheter is in the hole, it stays open. Once the catheter is removed the hole will close in 1-3 days. There are no restrictions with bathing or showering with a suprapubic tube. One study showed that in women, there were fewer bladder infections with a suprapubic tube than any other type of bladder management.



Advantages:

- Has all the advantages of a urethral catheter, and a suprapubic catheter also keeps you from feeling pain or discomfort from inserting and removing the catheter from your urethra.
- This catheter is easier to change than a urethral catheter. You do not need to lie down or undress to change the catheter.
- It is easy to keep the area around the catheter clean, and you are less likely to get an infection than with a urethral Foley catheter.
- It is preferable to a urethral catheter for sexuality reasons because the catheter is not in the urethra.

If the suprapubic catheter becomes blocked or can't be removed, the urethra can sometimes act as a "pop off valve" releasing some of the urine, or the urethra can be used to pass a temporary urethral catheter.

Disadvantages:

- Like urethral catheters, there is an increased risk for developing bladder stones and a smaller bladder.
- You may need to take medication to keep your bladder from being overactive and causing urinary leakage.
- Same day surgery is needed to create the opening for the catheter.

Reflex Voiding

This option primarily is used by men with bladders that fill and squeeze on their own because a convenient way to capture urine is needed.

- This method usually uses an external condom catheter. These catheters fit like a condom around the penis and connect to a tube and collection bag. (There is no effective external collecting device for women.)
- This method requires a relaxed sphincter, and you might need help relaxing it. Methods of relaxing your sphincter include suprapubic bladder tapping (where you lightly tap the area over your bladder), medication, injections, and surgery.
- A man or a woman who uses a reflex voiding option might decide to have their bladder drain directly into a protective undergarment. Undergarments must be changed frequently to avoid the urine causing a skin rash.

Advantages:

- You do not need to limit your liquids.
- You do not need to undress to empty your bladder.

Disadvantages:

- Men need to wear an external condom catheter, and a leg bag or a protective undergarment to collect urine.
- Women must use a protective undergarment.
- Protective undergarments must be changed frequently.
- The skin around the penis might get irritated from the condom catheter being too tight.
- The external condom might twist or kink and fall off during voiding.
- If you have a "retractile" penis that pulls back into the abdomen, especially when you sit up, the condom catheter might not stay on.
- Additional treatment or medication might be needed to relax your sphincter, and these treatments could cause side effects.

Valsalva and Credé Voiding

This option is for people who have difficulty getting their bladder to squeeze. Credé (pronounced kre-DAY) is a method where you push inwards with a closed fist over your bladder to empty it. Valsalva (pronounced vahl-SAL-vah) is a method where you tighten your abdominal muscles and bear down to force urine from your bladder.

- The amount of bladder emptying depends on how much force you use to push urine from the bladder and how much your sphincter relaxes.
- While not recommended, people sometimes use crede or valsalva voiding in addition to their other type of bladder management. For example bearing down when they catheterize themselves to try to make their bladder empty a little quicker by forcing the urine flow through the catheter quicker or bearing down and forcing a little urine out of their bladder so they do not catheterize themselves as often.

Advantages:

- You do not need to use a catheter of any kind.

Disadvantages:

- The pushing or straining to empty your bladder can cause problems over time (such as hemorrhoids, hernias, and other medical problems).
- To catch the urine, you will need to undress and transfer onto a toilet, use a bed pan, or wear protective undergarments.
- It often takes a lot of effort and time to bear down in an attempt to empty your bladder.
- You may not be able to empty your bladder completely leading to complications such as UTI's and bladder stones.

Sexual health video made by a friend:

https://youtu.be/Emh9HIPTT-8

Summary

- Following an SCI, maintaining healthy kidneys and a healthy bladder are important. There are many bladder management options.
- Your doctor can help you find the best option for your needs and lifestyle.
- Your doctor can also help you decide when an option is working well, or if a new option needs to be considered.

Reference

Consortium for Spinal Cord Medicine (2002). *Acute management of autonomic dysreflexia: individuals with spinal cord injury presenting to health-care facilities.* J Spinal Cord Med. 25, Suppl 1:S67-88.

Authorship

Bladder Management Options Following Spinal Cord Injury was developed by Todd A. Linsenmeyer, M.D., and Steven Kirshblum, M.D., in collaboration with the Model Systems Knowledge Translation Center.

Source: Our health information content is based on research evidence and/or professional consensus and has been reviewed and approved by an editorial team of experts from the Spinal Cord Injury Model Systems.

Appendix 10: Permission Letter from Siletha Ithemba NPO

Siletha Ithemba
Spinal Cord Peer Supporter NPO
NPO 232544
P/B X301 KwaNgwanase 3973
moseeh@gmail.com

Lauren Meagan Tomes

University of Witwatersrand

School of Therapeutic Services

Private Bag 3

Johannesburg

2050

Dear Ms Tomes,

The Non-profit organization Siletha Ithemba (NPO 232544) hereby grants permission to assist in the "bowel, bladder, and sexual problem in people with SCI: Experience and impact on mental health and quality of life" research study and the use of its client database as sample members.

Please note the following:

- Please ensure that you adhere to all the policies, procedures, protocols, and guidelines of the Department of Health with regards to this research.
- You will be expected to provide feedback on your findings to the organization.
- You are responsible for contacting Siletha Ithemba in order to provide feedback regarding your research findings.
- Please ensure the organization is advised well in advance of the commencement of the study as well as what will be expected of the organization's members.
- The client's decision, whether to participate in this study or not, is entirely left up to each individual client and Siletha Ithemba cannot speak on their behalf.
- Siletha Ithemba members will assist in the study during their allocated working hours unless otherwise discussed and agreed with them.

Yours Sincerely,

M.B Mthembu

Chairperson Siletha Ithemba

Appendix 11: Support Letter

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

Physical Address: 330 Langalibalele Street, Pietermaritzburg
Postal Address: Private Bag X9051
Tel: 033 395 2805/ 3189/ 3123 Fax: 033 394 3782
Email: hrkm@kznhealth.gov.za
www.kznhealth.gov.za

DIRECTORATE:
Health Research & Knowledge Management

Reference: KZ_202201_018
Enquiries: Mr X Xaba
Telephone: 033 – 395 2805

To: Ms LM Tomes
c/o HREC University of the Witwatersrand

RE: Letter of support for research

The Provincial Health Research Committee of the Department of Health has received a request for approval to conduct research in the department's health facility, titled "*Experience of Bowel, Bladder and Sexual Problems and the effectiveness of a health program on quality of life and mental health in people with SCI in Manguzi"*, reference number KZ_202202_018.

Although in principle the Department supports the study, we cannot process the application until we receive ethics approval. Please note that we do accept provisional/conditional ethics approval from a recognised research ethics committee.

I wish you all the best with your ethics application.

Yours Sincerely

Mr X. Xaba
Deputy Director: Health Research and Knowledge Management
10 February 2022

Appendix 12: DoH (NREC) Approval Letter

health
Department:
Health
PROVINCE OF KWAZULU-NATAL

Physical Address: 330 Langalibalele Street, Pietermaritzburg
Postal Address: Private Bag X9051
Tel: 033 395 2805/ 3189/ 3123 Fax: 033 394 3782
Email: [redacted]
www.kznhealth.gov.za

DIRECTORATE:
Health Research & Knowledge Management

NHRD Ref: KZ_202201_018

Dear Ms LM Tomes
(University of the Witwatersrand)

Approval of research

1. The research proposal titled **'Experience of Bowel, Bladder and Sexual problems and the effectiveness of a health program on quality of life and mental health in people with Spinal Cord Injury (SCI) in Manguzi'** was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).

   The proposal is hereby **approved** for research to be undertaken at Manguzi Hospital.

2. You are requested to take note of the following:
   a. *All research conducted in KwaZulu-Natal must comply with government regulations relating to Covid-19. These include but are not limited to: regulations concerning social distancing, the wearing of personal protective equipment, and limitations on meetings and social gatherings.*
   b. *Kindly liaise with the facility manager BEFORE your research begins in order to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.*
   c. *Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.*
   d. *Provide an interim progress report and final report (electronic and hard copies) when your research is complete to* ***HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200*** *and e-mail an electronic copy to hrkm@kznhealth.gov.za*
   e. *Please note that the Department of Health shall not be held liable for any injury that occurs as a result of this study.*

For any additional information please contact Mr X. Xaba on 033-395 2805.

Yours Sincerely

Dr E Lutge
Chairperson, Health Research Committee
Date: 14/05/2022.

Fighting Disease, Fighting Poverty, Giving Hope

Appendix 13: HREC Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R49 Miss LM Tomes

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M210813

NAME: (Principal Investigator)	Miss LM Tomes
DEPARTMENT:	School of Therapeutic Sciences Department of Physiotherapy Medical School University
PROJECT TITLE:	*Bowel, bladder and sexual problems in people with spinal chord injuries: experience and impact on mental health and quality of life*
DATE CONSIDERED:	2021/08/27
DECISION:	Approved unconditionally
CONDITIONS:	
NOTE:	If contact information regarding student study participants is required, please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>
SUPERVISOR:	Ms S Pilusa
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2022/03/03

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

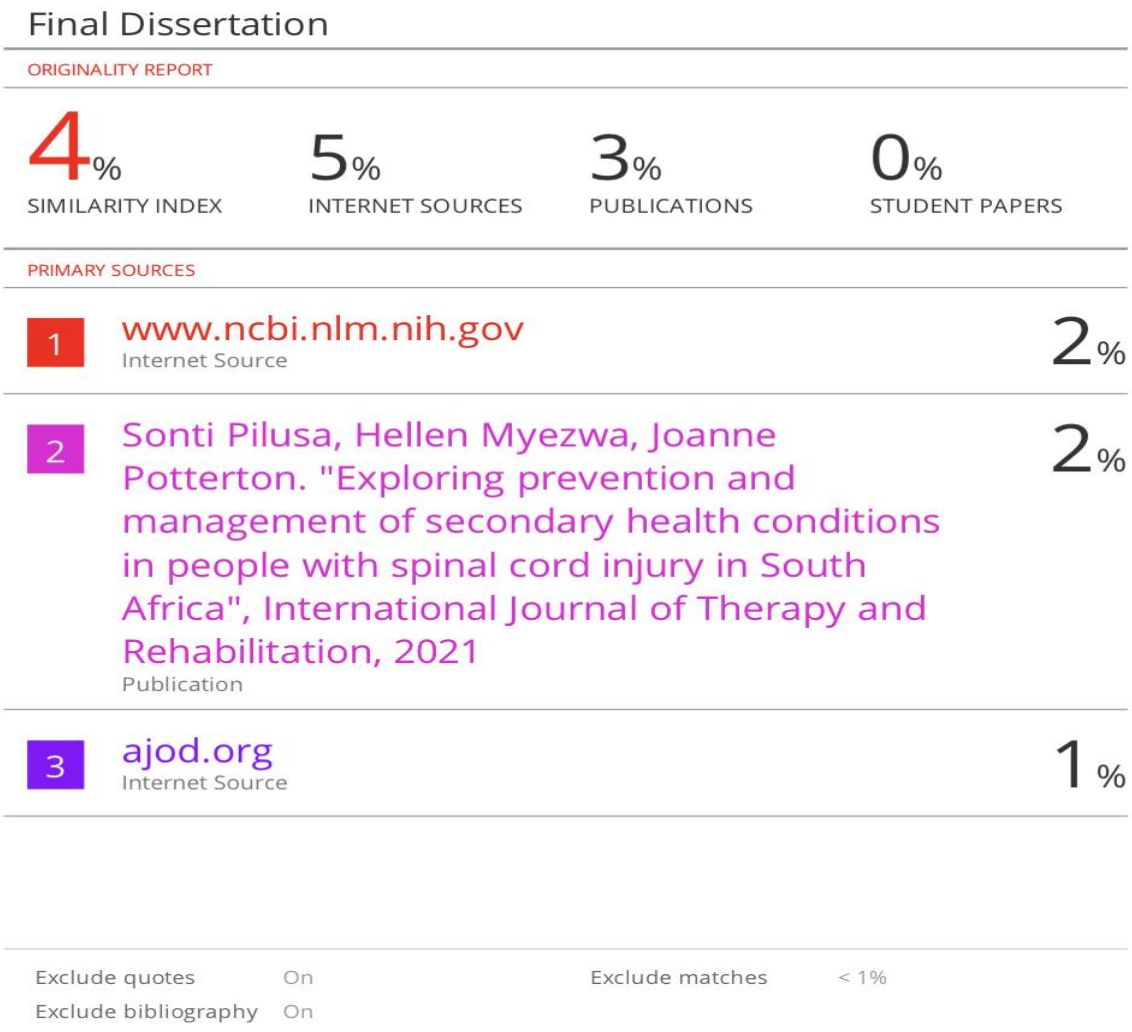
DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **August** and therefore reports and re-certification will be due in the month of **August** each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Signature of Principal Investigator — Date: 05/03/2022

Appendix 14: TurnIt In Plagiarism Report



Final Dissertation

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3	ajod.org Internet Source	1%

Exclude quotes	On	Exclude matches	< 1%
Exclude bibliography	On		

Appendix 15 Master of Science in Physiotherapy: Approval of Title

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

06 January 2023
Person No: 549127
PAG

Miss LM Tomes
12 Walden Lane
Alan Manor
Mondeor
2091
South Africa

Dear Miss Lauren Tomes

Master of Science in Physiotherapy: Approval of Title

We have pleasure in advising that your proposal entitled *Experience of bowel, bladder and sexual problems and the effectiveness of a health program on quality of life and mental health in people with SCI in Manguzi* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

100 1922 2022