



LIFE EXPERIENCES AND PERCEIVED COMMUNITY REINTEGRATION OF PEOPLE WITH SPINAL CORD INJURY AFTER HOSPITAL DISCHARGE IN MALAWI

A Research Report Submitted to the Faculty of Health Sciences, the University of the Witwatersrand in partial fulfilment of the requirements for the degree of Master of Science in Physiotherapy, Johannesburg, 2025

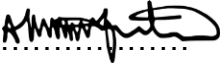
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DECLARATION

I, Aaron Mwafulirwa, declare that this Research Report is my unaided work. It is being submitted for the degree of Master of Science in Physiotherapy: Neurology and Neurosurgery for physiotherapists at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other university.

Signed.....

1st day of June 2025 in Malawi.

ABSTRACT

Spinal cord injury (SCI) is described as a complex condition that disrupts life and results in profound impairments and functional loss. Despite efforts of rehabilitation professionals to improve the functional independence of people with spinal cord injury (PWSCI) for their successful community reintegration, PWSCI face challenges to achieving significant community reintegration levels which is its primary goal. This study aimed to explore the life experiences and perceived community reintegration of PWSCI who were at least 6 months post-hospital discharge in Blantyre, Malawi. This qualitative study used a phenomenological approach and participants who were purposively sampled. Thirteen voluntarily consenting participants took part in the study. Their mean age was 38.1 years (SD 12.38). Their mean duration of living with SCI was 3.2 years (SD 1.21), with the mean length of hospital stay being 5.1 months (SD 2.40). Data were collected through semi-structured interviews using an interview schedule. The interviews were digitally recorded and transcribed verbatim. Thematic content analysis was used during data analysis in which codes were grouped, and themes were generated. Three objectives were explored in this study. Five themes emerged under the objective of exploring the challenges facing PWSCI in relation to community reintegration, namely, limited community participation, experience of vocational challenges, presence of secondary health conditions, experience of lack of resources, and restrictive environment. The study also explored the coping strategies that PWSCI use to mitigate the challenges they face and four themes emerged: having effective social support, spiritual health and accepting change, becoming self-reliant, and managing life with available resources. Finally, the study sought suggestions from PWSCI on ways to further improve their community reintegration and two themes emerged, namely, community proactiveness in environmental modifications and effective preparedness of PWSCI for home. The study findings highlight the need for a collective effort from various stakeholders to address the challenges PWSCI face and reinforce the coping strategies they adopt to facilitate successful community reintegration.

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LIST OF ABBREVIATIONS

ADL	Activities of daily living
COMREC	College of Medicine Research Ethics Committee
KUHES	Kamuzu University of Health Sciences
KCH	Kamuzu Central Hospital
KRC	Kachere Rehabilitation Centre
LMICs	Low and Middle-Income Countries
LOS	Length of stay
OBR	Outcome-Based Rehabilitation
PWSCl	People with spinal cord injury
QECH	Queen Elizabeth Central Hospital
QoL	Quality of life
SCI	Spinal Cord Injury
SHCs	Secondary Health Conditions
TSCI	Traumatic Spinal Cord Injury

LIST OF DEFINITIONS

Community reintegration: The resumption of culturally and developmentally appropriate social roles after spinal cord injury (Anderson et al., 2024)

Spinal cord injury: Damage to the spinal cord resulting in temporary or permanent loss of motor, sensory and autonomic function.(Ahuja et al., 2017)

The International Classification of Functioning, Disability and Health (ICF): A standardised and comprehensive framework for describing functioning and disability in relation to a health condition. (Stojic et al., 2025)

CHAPTER 1: INTRODUCTION AND SCOPE OF THE RESEARCH REPORT

1.1 Introduction

In this chapter, the background information on spinal cord injury (SCI) and the community reintegration of people with spinal cord injury (PWSCI) is provided. The chapter also articulates the problem statement, the research question, the aim of the study and the specific objectives of the study. Furthermore, the significance of the study is highlighted. Finally, the chapter is concluded by giving an outline of the rest of the document to guide the reader.

1.2 Background of the study

Spinal cord injury (SCI) is described as a complex condition that disrupts life and results in profound impairments and functional loss (Ahuja et al., 2017). According to estimates, the incidence rate of SCI is four times higher in men than in women, with an estimated 10 to 83 cases per million people worldwide. Of all SCI cases, quadriplegia accounts for 52%, while paraplegia is estimated at 42% (Barrett, Barman, Brooks and Yuan, 2019). The incidence rates of SCI differ by region; for example, North America reported in 2019 the highest age-standardised incidence rate of 22 (95% UI 17 to 29) cases per 100 000 population, while Australia reported 15 new cases per million annually (Safdarian et al., 2023). In Africa, Joseph et al. (2015) reported an incidence rate of 75.6 per million. The prevalence of SCI has ranged between 236.0 and 1,298.0 per million people over the last decades, and traumatic spinal cord injury (TSCI) accounts for 90% of SCI injuries, with Jesuyajolu et al. (2023) reporting road traffic accident as the major contributor to SCI incidence with 44%. A recent study conducted at Kamuzu Central Hospital (KCH) reported cervical SCI as the most common type of injury (41.3%) and motor vehicle accidents as the leading cause of injury (45.7%) (Eaton, Mukuzunga, Grudziak and Charles, 2019).

Although rehabilitation of people with spinal cord injury (PWSCI) in many countries is similar, studies indicate that PWSCI are not adequately prepared for successful community reintegration as the primary goal is to restore function (Du Plessis et al., 2018). For example, in Malawi, patients are referred to Kachere Rehabilitation Centre (KRC) for intensive rehabilitation. The primary aim of the multidisciplinary team at KRC is to restore function of PWSCI in various activities of daily living (ADLs). The multidisciplinary team also assesses the home environment for possible adjustments and modifications to facilitate a smooth transition of PWSCI from hospital to home. However, the modifications do not address the community at large, and follow-up of patients after discharge is poor (Glickman et al., 2015).

The transition of life from hospital to community may not be as smooth as expected. Community reintegration is defined as the resumption of culturally and developmentally appropriate social roles after spinal cord injury (Anderson et al., 2024). People with SCI are ideally thought to achieve community reintegration successfully if they demonstrate participation in three related domains, namely, home integration, social integration, and productive integration (Kratz et al., 2015). The various types of participation will, therefore, range from actively being involved in affairs at home such as meal preparations, going for trips (including shopping), managing finances, and being able to be involved in income-generating or educational activities (Ahmed, Quadir, Rahman and Alamgir, 2018). There is need for PWSCI to be adequately prepared for home before discharge from hospital to achieve successful community reintegration. However, literature indicates that rehabilitation professionals do not focus on comprehensively preparing the PWSCI for the 'real world' after discharge, thus resulting in PWSCI perceiving themselves to take a while to get used to the new environment and be able to participate in different activities at family and community level (Du Plessis et al., 2018).

Many PWSCI regard the environment as challenging in terms of accessibility of services and mobility within the home and the community at large after discharge from the rehabilitation unit (de Serres-Lafontaine et al., 2023; Mohan and Deb, 2024). This is attributed to self-perceptions of fear of leaving their homes and viewing the outside environment as insecure and the reactions of other people who stigmatise them because of the injury (Engblom-Deglmann and Hamilton, 2020). While Henderson and Mashola (2024) found a good community reintegration of people with paraplegia (78%), another study reported that PWSCI found community reintegration difficult to achieve as their physical deficits worsened their experience of adjusting to a new life after discharge from hospital, over and above a challenging environment (Fuseini, Aniteye and Alhassan, 2019). Of great importance is the loss of the autonomy of PWSCI, as they may need to depend on family members to do some tasks such as mobility and other ADLs due to loss of function. Other negatively impacted tasks that were reported by Fuseini et al. (2019) included the inability to fulfil marital duties and participate in social groupings due to bladder and bowel incontinence. Generally, PWSCI achieve low community reintegration scores in aspects of functional independence, mobility, and social integration, with mobility being the greatest barrier (Ahmed, Quadir, Rahman and Alamgir, 2018).

A SCI leaves the affected individual with lifelong physical, psychological and social changes (Nas et al., 2015; Lim et al., 2017). Therefore, the importance of exploring the life experiences of PWSCI cannot be overemphasised. Studies that explored life experiences of PWSCI post-

discharge revealed that the participants reported experiencing physical effects of the injury such as pain, difficulties in bladder and bowel control, autonomic dysreflexia, and development of pressure ulcers, which all negatively affected their functioning and social participation (Mazwi, Adeletti and Hirschberg, 2015; Eldahan and Rabchevsky, 2018). In another study, there was onset of anxiety and depression among participants (Lim et al., 2017). Despite several studies indicating that PWSCI experience a lot of problems including anxiety and depression, Fuseini et al. (2019) positively found that participants experienced a deeper relationship with family members and their spouses after injury.

To our knowledge, few published studies in Malawi explored community reintegration of people with disability (Chimatiro and Rhoda, 2014; Glickman et al., 2015). While these studies provide us with baseline knowledge of community reintegration of people with disability in general, it is important to explore the life experiences and perceived community reintegration specific to PWSCI.

1.3 Problem Statement

Spinal cord injury is known to affect PWSCI negatively, leading to difficulty with mobility, reduced social participation, and psychological problems. There is a dearth of African literature investigating community reintegration and life experiences of PWSCI after hospital discharge, particularly in Malawi. The studies conducted in Malawi have only focused on the epidemiological trends of SCI and community reintegration for people with disability in general (Glickman et al., 2015; Eaton, Mukuzunga, Grudziak and Charles, 2018). During the researcher's clinical experience, he observed that most discharged PWSCI complained of difficulties with access to quality medical rehabilitation care, inability to meet appointments with rehabilitation officers due to lack of transport money and long distance, and a high rate of rehospitalisation after initial discharge.

1.4 Research Question

What are the life experiences and perceived community reintegration of PWSCI who are at least 6 months post-hospital discharge in Malawi?

1.5 Aim of the Study

This study aimed to explore the life experiences and perceived community reintegration of PWSCI who are at least 6 months post-hospital discharge in Blantyre, Malawi.

1.5.1 Objectives

- To explore the challenges related to community reintegration experienced by the PWSCI after discharge
- To explore the coping strategies used to mitigate against the challenges faced.
- To seek their suggestions on ways to further improve their community reintegration.

1.6 Significance of the Study

Results from this study will bridge the literature gap and expand the knowledge base on life after SCI in Malawi. The study results can also be used to develop awareness programs in hospitals and rehabilitation centres for rehabilitation professionals in planning adequate and effective patient rehabilitation approaches aimed at preparing SCI patients for successful community reintegration. Finally, the study will create a benchmark for further studies aimed at interventions to improve the quality of life (QoL) of PWSCI.

1.7 Outline of the chapters

In chapter 1, the background information on spinal cord injury (SCI) and the community reintegration of people with spinal cord injury (PWSCI) is provided. The chapter also articulates the problem statement, the research question, the aim of the study and the specific objectives of the study. Finally, the significance of the study is highlighted in this chapter.

In chapter 2, a comprehensive review of the literature on spinal cord injury and its epidemiological trends is provided. The chapter also discusses the conceptual framework of the study. Furthermore, outcome-based rehabilitation in relation to community reintegration is discussed. The chapter also gives a detailed review of literature on community reintegration at the levels of the body function and structure, activity limitations, and participation restriction in the context of environmental and personal factors.

In chapter 3, all the methods used to achieve the study objectives are outlined. The chapter outlines the areas such as study type, setting, inclusion and exclusion criteria, sampling methods, data collection tools used and the data collection process. Furthermore, the chapter outlines the data management and analysis processes used and addresses all the ethical issues in the study.

Chapter 4 provides the results of the study which are presented in narrative format, tables and figures.

Chapter 5 provides a discussion of the qualitative results presented in chapter 4. In this chapter, the results are compared and contrasted with the literature.

Chapter 6 provides the conclusion and recommendations of the study. It further presents the reflexivity of the researcher

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter discusses an overview of the literature on SCI and its epidemiological trends. It further discusses outcome-based rehabilitation concerning community reintegration. The International Classification of Functioning, Disability and Health (ICF) was used as the conceptual framework for the literature review. Using the framework, the chapter discusses the community reintegration of people with spinal cord injury (PWSCI) at the levels of body function and structure, activity limitations, and participation restriction in the context of environmental and personal factors.

Literature was searched from google scholar and PubMed databases. The search was limited to literature on people with spinal cord injury, written in English and published in the last ten years. The search terms were made by combining the keywords using a semicolon (;) or using Boolean terms as follows:

- “spinal cord injury”; “general facts”
- “people with spinal cord injury” AND “community reintegration”
- “spinal cord injury”; “epidemiology”,
- “people with spinal cord injury”; “outcome-based rehabilitation”
- “spinal cord injury”; “body structure and function”
- “spinal cord injury”; “activity limitations”
- “spinal cord injury”; “participation restrictions”
- “spinal cord injury” ; “environmental barriers”
- “spinal cord injury” ; “environmental facilitators”
- “spinal cord injury” AND “sexual dysfunction”
- “spinal cord injury”; “secondary health conditions”
- “people with spinal cord injury” AND “personal factors”
- “people with spinal cord injury” AND “psychological factors”

2.2 Spinal Cord Injury Overview

Injury to the spinal cord happens suddenly from traumatic events or insidiously from non-traumatic events and it results in severe, drastic changes to the life of an individual (WHO, 2013). These changes may include physical, psychological, and social consequences, which have a far-reaching

effect on an individual's life. SCI can be classified as traumatic and non-traumatic. SCI can result in paraplegia or tetraplegia depending on the level of spinal cord that is injured (NSCISC, 2016). Paraplegia is the paralysis of the lower part of the body, often involving the lower limbs and the affected trunk (NSCISC, 2016). Conversely, tetraplegia is the paralysis of the trunk, upper and lower limbs, and spinal cord following damage to the cervical region (ref).

2.3 Epidemiological trends of spinal cord injury

2.3.1 Prevalence and Incidence

The burden of SCI has increased in the past 30 years globally, with 20.5 million PWSCI in the year 2019 (Ding et al., 2022). The global incidence of SCI has increased over the last decade up to 23.77 cases per million people (Lu, Shang, Zhang, Pang, Hu, Dai, Shen, Wu, Liu, Luo, et al., 2024). Traumatic SCI (TSCI) was predominant, with an incidence rate of 26.48 cases per million people, while non-traumatic SCI was at a rate of 17.93 cases per million people, with males 3.2 times more affected than females in the 21- 41 years age group (Lu, Shang, Zhang, Pang, Hu, Dai, Shen, Wu, Liu and Luo, 2024).

The incidence of SCI varies from region to region, with high-income countries in North America and Europe having relatively higher incidence rates. For example, there is an estimated annual incidence rate of SCI in the United States of America as 54 cases (95% CI,53-55) per million population and 32 cases per million people in Canada (Jain et al., 2015; Thorogood et al., 2023). The United Kingdom's reported annual incidence rate is 19 cases per million population (Patek and Stewart, 2023) and ranges from 21.0 per million to 32.3 per million population in Australia (New, Baxter, Farry and Noonan, 2015). The SCI incidence rate in China ranged from 14.6 to 60.6 cases per million population (Chen et al., 2022).

According to a systematic review of 23 developing countries, the pooled incidence of TSCI in LMICs varied between 13.52 and 37.62 cases per million annually between 2009 and 2020 (Golestani et al., 2022). The incidence of NTSCI in LMICs ranges from 13.30 to 23.26 cases per million, with Golestani et al. (2022) reporting an incidence rate of 10.23 cases per million in Pakistan and 75.6 cases per million in South Africa.

In Sub-Saharan Africa, the prevalence of TSCI varies; in Botswana, it has been reported to be 13 per million people (Lofvenmark et al., 2015), whereas in South Africa, it has been reported to be

75.6 per million people (Joseph et al., 2015). In Tanzania, the incidence of SCI was more than 26 cases per million population between 2010 and 2014 (Moshi, Sundelin, Sahlen and Sörlin, 2017).

In Malawi, there is a lack of reporting mechanisms for new cases of SCI, and as such, no epidemiological studies have reported accurate estimates of the incidence of SCI. However, some epidemiological studies reported the incidence of mortality of SCI was estimated to range from 23.5 to 29.8 per 100,000 per year (Manning Smith et al., 2022). Furthermore, the most common cause of SCI in Malawi was reported to be falls from a height, followed by road traffic accidents (Chokotho et al., 2022), similar to findings by Moshi (2018).

2.4 Outcome Based Rehabilitation and community reintegration of people with spinal cord injury

Rehabilitation is key to preparing PWSCI for successful community reintegration. Rehabilitation professionals can achieve this by adopting outcome-based rehabilitation (OBR), a five-level approach describing how PWSCI progressively achieves functional recovery and independence to achieve community reintegration (Karakuzu Gungor, 2024). In the first level, individuals with SCI are managed in acute care

units, focusing on vital function stabilization and prevention of life-threatening complications (Nas et al., 2015). All medical issues are managed at this level. In the second level, rehabilitation aims to achieve basic self-care independence such as grooming, feeding, and other functions. In the third level, rehabilitation aims at the residential integration outcome in PWSCI and focuses on enabling PWSCI to navigate their home environment and perform self-care activities (Nas et al., 2015). To facilitate residential integration, rehabilitation professionals often make adaptations and train PWSCI wheelchair mobility skills and caregiver management.

Furthermore, level four involves enabling PWSCI to achieve community reintegration in areas such as participation in recreational, religious, cultural, educational, and vocational activities (Musselman, Papadimitriou and Vasilchenko, 2022). Rehabilitation aims at enhancing infrastructural accessibility and social inclusion at this level. After achieving community reintegration in level four, PWSCI are finally progressed to level five which aims at enabling them to achieve social participation in different areas of life. At this level, PWSCI can participate in various community activities and social roles, professional engagement, leadership, and vocational activities (de Serres-Lafontaine et al., 2023).

Although the highest level is social participation, the primary aim of rehabilitation is to achieve level three, residential integration, in which PWSCI can live a functionally independent life at home (Barclay, Robins, Migliorini and Lalor, 2021). In so doing, they are mostly discharged from the hospital without achieving levels four and five, and this leaves them with no prerequisite skills to participate in activities of the broader community. Consequently, PWSCI are left struggling to achieve community reintegration. A multidisciplinary approach must be adopted in efforts to make PWSCI achieve successful community reintegration. Effective rehabilitation programs should ensure that efforts are made to enhance participation through adaptive technologies and vocational training programs, which are crucial for successful community reintegration.

2.5 Conceptual Framework: The International Classification of Functioning, Disability and Health (ICF)

The International Classification of Functioning, Disability and Health (ICF) model describes community reintegration as a crucial part of an individual's participation in community activities after disability. The ICF model is a tool used by health professionals to categorize functioning, disability, and health (Mitra and Shakespeare, 2019). The model emphasises the importance of setting rehabilitation goals aimed at preparing PWSCI for successful community reintegration. Therefore, the ICF model guides rehabilitation professionals to enable PWSCI to participate in work, education, leisure activities, and other community activities, and it considers environmental and personal factors (Olckers, 2017).

Since the model is useful for outlining issues that PWSCI face and is crucial for developing rehabilitation plans of successful community reintegration, it was used in this study to explain and explore community reintegration and the life experiences of PWSCI.

2.6 Factors affecting community reintegration of people with spinal cord injury

2.6.1 Body structure and function

The ICF model defines body structure and function as the anatomical, physiological, and psychological aspects of the body that determine the body's ability to function optimally (Mitra and Shakespeare, 2019). When an individual sustains SCI, there is damage to the spinal cord, leading to severe anatomical changes that can lead to a loss of innervation of effector organs, resulting in several physiological problems such as weakness and atrophy of muscles, loss of sensation, pressure sores, pain, bowel and bladder incontinence, autonomic dysreflexia and sexual dysfunction (Rust and

Kaiser, 2017; Chambel, Tavares and Cruz, 2020; Zizzo, Gater, Hough and Ibrahim, 2022).

The level and severity of SCI determine the expected functional outcomes of an individual and this has an impact on their community reintegration. The spinal cord is divided into five segments, namely, the cervical (C1-C8), thoracic (T1-T12), lumbar (L1-L5), sacral (S1-S5) and coccygeal segments (Rupp et al., 2021). Rupp et al. (2021) describe the level of SCI as the lowest segment of the spinal cord which has normal sensory and motor function on both sides of the body. An injury to any level determines the extent of functional loss and the residual functional abilities of an individual. When an individual sustains an injury to the higher cervical regions of the spinal cord (C1-C4), they lose the function of the respiratory muscles and need ventilatory support and personal support all the time (Javeed et al., 2023). The ventilator support limits their mobility within their community, thereby making outdoor activities difficult to achieve (Nas et al., 2015). Another problem is the increased susceptibility to respiratory infections, autonomic dysreflexia and pressure sores which makes them unable to participate in public activities (Nas et al., 2015). The difficulties that PWSCI experience in wheelchair mobility due to muscle weakness in upper and lower limbs negatively affect their participation in many areas such as forming new relationships, participating in different community activities, and other recreational activities (Jørgensen, Iwarsson and Lexell, 2017). On the other hand, individuals with lower cervical region (C5-C6) can use some adaptive devices in areas of self-care and mobility (Nas et al., 2015). However, participation of PWSCI in community activities is significantly reduced, and they generally achieve low community reintegration. In both situations, the individual loses the function in both upper and lower limbs, a condition called tetraplegia (Rupp et al., 2021).

Furthermore, individuals with thoracic SCI have a considerably better level of functional independence as their upper limb function is preserved. These individuals can propel the wheelchair and perform transfers and self-care activities independently. This independence in mobility enables them to participate in various community activities, including recreational activities and vocational training (Olckers, 2017). Lastly, individuals who sustain lumbar and sacral injuries have more functional independence than those with higher-level injuries and can use a wide range of assistive devices and orthotics to improve their mobility and consequently have a better level of community reintegration (Satone et al., 2022). This means that individuals with high-level SCI have more functional limitations and barriers in accessing public spaces, workspace, and transport, thereby achieving low levels of community reintegration, unlike those with low-level SCI.

The severity of SCI is described as the extent to which the spinal cord is damaged (Rupp et al.,

2021). Two terms are used to describe the severity of SCI, namely, complete and incomplete SCI. Complete SCI is the type of SCI in which an individual has a total loss of sensory and motor function below the level of injury (Nas et al., 2015; Rupp et al., 2021). Complete SCI is characterised by a loss of sensory and motor function of the anal muscles which are controlled by the sacral segments (S4-S5) of the spinal cord. In contrast, the incomplete SCI is characterised by an injury to the spinal cord with preservation of some sensory and motor function below the level of injury, including the sparing of the sacral function (Rupp et al., 2021).

The America Spinal Injury Association Impairment Scale (AIS) is used to classify the severity of SCI into five grades. For complete SCI, ASIA A is characterised by a total loss of sensory and motor function in the sacral segments (S4-S5) and there is a complete loss of function of the limbs and trunk below the level of injury (Rayegani, Oraee-Yazdani and Tavanaei, 2023). Incomplete SCI has three grades, namely, AIS B, ASIA C and ASIA D in order of decreasing severity (Nas et al., 2015; Rayegani, Oraee-Yazdani and Tavanaei, 2023). ASIA B is the most severe grade of the three grades with individuals having a preserved sensory function but not motor function below injury. Individuals with ASIA C have more than half of key muscles with muscle grade of less than 3 while those with ASIA D have majority of the muscles with grade of greater than 3 (Rayegani, Oraee-Yazdani and Tavanaei, 2023). The classification of ASIA E entails that an individual has normal sensory and motor function and have no neurological problems.

People with spinal cord injury with severe forms of SCI (ASIA A and B) experience difficulties to perform various activities of daily living and ultimately struggle to participate in activities in homes and the community at large. In contrast, PWSCI with ASIA C and D have more potential to achieve functional independence, leading to better community reintegration than PWSCI with ASIA A and ASIA B forms of SCI (Jørgensen, Iwarsson and Lexell, 2017; Rupp et al., 2021).

2.6.2 Activity limitations

Activity limitation is described as the challenges that people with spinal cord injury experience in performing various tasks due to motor and sensory impairments after the injury and they include mobility, bladder and bowel management, cooking, feeding, grooming, bathing and dressing, with pain being attributed to most of these activity limitations (Middleton et al., 2022).

The extent of activity limitations in PWSCI is dependent on the level and severity of SCI in which high levels of SCI and severe forms of SCI (ASIA A and B) lead to serious sensory and motor

impairments, resulting in serious activity limitations, thereby achieving low community reintegration (Jørgensen, Iwarsson and Lexell, 2017). One of the activity limitations that PWSCI struggle with is mobility which is associated with low community reintegration as they are unable to navigate within their home and community for various activities such as shopping, religious events, sporting activities and other recreational activities (Gretschel, Visagie and Inglis, 2017).

The environmental context is also a crucial determinant of activity limitations among PWSCI (Lijodi, Titus, Louw and Joseph, 2024). People with spinal cord injury in Low and Middle-Income Countries (LMICs) often face challenges in achieving participation in various activities due to lack of appropriate resources for mobility and self-care, leading to low quality of life (Halvorsen et al., 2021). Even though PWSCI in LMICs achieve some mobility with the help of assistive devices, the inappropriate wheelchair designs, high cost of maintenance, coupled with environmental barriers of inaccessible buildings, hilly terrain and poor road networks pose a monumental challenge for PWSCI to achieve community reintegration (Ekiz, Demir and Özgirgin, 2014; de Serres-Lafontaine et al., 2023). However, in high-income countries, where resources such as wheelchairs and other assistive technologies are readily available at affordable prices, and the environment has good terrain, accessible buildings, and good road networks, PWSCI achieve relatively higher levels of community reintegration than in LMICs. For example, in Malaysia, a study found that being able to drive a car improved mobility and functional independence of PWSCI and resulted in improved their QoL (Lee, Hasnan and Engkasan, 2018).

Another area in which PWSCI face challenges in activity limitations is self-care which encompasses areas such as performing activities such as feeding, bathing, hygiene, bowel and bladder care, dressing, toileting, and other activities (Abu-Baker, Al-Zyoud and Alshraifeen, 2021). The level of independence in performing these activities is dependent on the level and severity of SCI that an individual sustains, with evidence showing that people with incomplete SCI or paraplegia often have a high ability to achieve self-care (LaVela, Etingen and Miskevics, 2016). Complete SCI with a high level of injury is known to significantly reduce an individual's ability to perform various self-care activities independently and, ultimately, a good QoL (Abu-Baker, Al-Zyoud and Alshraifeen, 2021; Mugisa, Kironde and Mwaka, 2023).

PWSCI who are unable to perform self-care activities independently and have no one to assist them are ashamed of taking part in recreational and community activities because they feel unclean and cannot cope with the embarrassment associated with it (Pilusa, Myezwa and Potterton, 2021). Therefore, it is of paramount importance that rehabilitation professionals focus on training PWSCI

with the appropriate skills so that they can achieve a level of independence in self-care activities (Zwecker et al., 2022). They should also focus on facilitating a positive social environment for the PWSCI using a good support system by involving caregivers, community members, and rehabilitation institutions to provide the necessary support to PWSCI regarding self-care as recommended by Abu-Baker, Al- Zyoud and Alshraifeen (2021). The use of good support system can boost the confidence of PWSCI to participate in various activities at family and community levels, thereby improving their community reintegration.

2.6.3 Participation restrictions

The term “participation” is defined as an individual's involvement in their life's situation and this may include performing daily routines, driving, going for leisure and recreational activities, and forming intimate relationships (Mohan and Deb, 2024). Spinal cord injury results in functional deficits that have an impact on the level of an individual's participation in various activities, leading to participation restrictions, which are problems that an individual experiences during their involvement in life activities (Craig et al., 2015).

Participation restrictions among PWSCI have been extensively explored in recent years and findings reveal an interplay of physical functional deficits and environmental barriers in causing participation restrictions that PWSCI experience in their community (Craig et al., 2015; Halvorsen et al., 2021; de Serres-Lafontaine et al., 2023; Mohan and Deb, 2024). One study found that PWSCI experienced difficulties in doing their livelihood activities and ADLs due to environmental barriers such as inaccessible public places and buildings (de Serres-Lafontaine et al., 2023). This inaccessibility was due to the presence of steps into the buildings, uneven entrances, narrow doors, and the absence of ramps, limiting their mobility and access to the upper levels of buildings. As a result, PWSCI achieved poor social participation in terms of buying and selling things and accessing medical facilities and other important government offices.

Inaccessibility of public places in Kenya was also the main environmental barrier that led to participation restrictions among PWSCI, mostly when using public transportation and public places (Lijodi, Titus, Louw and Joseph, 2024). Another study showed that factors such as attitudes of colleagues, family, and relatives influenced the participation of PWSCI who reported to have experienced challenges in forming intimate relationships, using public places, and going out for recreational activities and leisure (Yang et al., 2023). Furthermore, de Serres-Lafontaine et al.

(2023) reported that PWSCI struggled to go to church, school, shops, and other outdoor activities, meaning they failed to leave their home environment to participate in activities in the wider community.

The problem of reduced participation is compounded by the presence of secondary health conditions (SHCs) such as pressure sores, bowel and bladder dysfunction, pain, sexual dysfunction, and urinary tract infections which are associated with a significant reduction in QoL among PWSCI (Adriaansen et al., 2016; Pilusa, Myezwa and Potterton, 2021). The presence of SHCs, especially pain, pressure sores, and urinary tract infections, often forces PWSCI to stay in bed for prolonged periods, thereby reducing their participation in community activities (Pilusa, Myezwa and Potterton, 2021). Other SHCs such as bladder and bowel dysfunction interfere with PWSCI's ability to form social relationships due to the permanent presence of catheters and bladder and bowel leakages which cause PWSCI to have a sense of embarrassment (Braaf, Lennox, Nunn and Gabbe, 2017; Pilusa, Myezwa and Potterton, 2021). This feeling of embarrassment makes it harder for them to leave their homes to public places and participate in various social activities, thus achieving low levels of community reintegration.

Reduced levels of participation among PWSCI are associated with low QoL and this reduces their community reintegration (Halvorsen et al., 2021). Therefore, rehabilitation teams should be encouraged to focus on participation as it is crucial in achieving successful community reintegration. Issues of accessibility and SCHs should be comprehensively addressed to enhance the community reintegration of PWSCI.

2.6.4 Environmental factors

Rehabilitation professionals should consider the environment to which they are discharging an individual with SCI to ensure successful community reintegration and not have PWSCI struggle to adjust to their old environment (Mukaino et al., 2020).

Studies in high-income countries indicate that PWSCI achieve relatively higher levels of community reintegration due to environmental facilitators, namely, a well-developed rehabilitation system, a conducive social environment with good family and community support, availability of resources such as assistive devices and advanced technology devices which facilitate the participation of PWSCI (Barclay, McDonald and Lentin, 2015; Ruoranen, Post, Juvalta and Reinhardt, 2015; Pan

et al., 2024). The environment with adequate and appropriate resources gives the PWSCI an opportunity to reintegrate into their community with relative ease as they can participate in various activities at family and community levels.

In Low and Middle-Income Countries, PWSCI face various challenges in their quest for successful community reintegration, with studies indicating that they achieve low levels of community reintegration after being discharged from the hospital (Ahmed, Quadir, Rahman and Alamgir, 2018; Akter et al., 2019). Akter et al. (2019) found that environmental barriers such as inaccessibility to architectural infrastructure restricted PWSCI in their attempts to use public buildings in Bangladesh, as the poor designs of houses that only had stairs prevented wheelchair users from using the houses. They further found that uneven, muddy terrain and road networks massively reduced the accessibility of the community, thereby significantly reducing their community reintegration. Other studies also concurred with similar findings. For example, similar environmental barriers were found in South Africa, with Vermaak (2016) reporting that inaccessible public buildings, shops, recreational centres, and hospitals make life even harder for PWSCI to get involved in community activities. Glickman et al. (2015) in Malawi echoed that environmental barriers such as poor road networks, hilly terrain, inaccessible public services, and markets play a major role in limiting participation in their homes and community.

The social environment also plays a big role in the community reintegration process of PWSCI. In most communities, PWSCI experience negative societal attitudes which affected their social participation with studies reporting PWSCI were ridiculed, insulted, rejected, disregarded, looked down on, not seen as proper human beings and being misunderstood when using public places such as shops, buses and trains (Barclay, McDonald, Lentin and Bourke-Taylor, 2016; Lofvenmark, Norrbrink, Nilsson Wikmar and Lofgren, 2016). With this negative social environment, PWSCI often withdraw from participating in public activities with other members of the community as they feel they are targeted by people with negative attitudes, thereby leading to a decline in community reintegration (Lofvenmark, Norrbrink, Nilsson Wikmar and Lofgren, 2016).

Preparing PWSCI for hospital discharge while aiming at successful community reintegration should include skill training in areas of mobility, self-care, respiratory care, vocational counselling, coping strategies, peer mentoring and pressure management (Glinsky and Harvey, 2024). Most importantly, rehabilitation professionals must also consider making a conducive social environment by facilitating an effective social support of family, peer support groups, religious leaders and community members

(Nizeyimana, Louw and Joseph, 2025). However, a scoping review of Barclay, Robins, Migliorini and Lalor (2021) found that most rehabilitation programs often focus on education on physical functional needs and community mobility, and do not address the social aspect of the life of PWSCI. Literature highlights the importance of addressing the environmental barriers to social participation of PWSCI as a catalyst for successful community reintegration (Reinhardt, Ballert, Brinkhof and Post, 2016; de Serres-Lafontaine et al., 2023). Therefore, it is recommended that rehabilitation programs should also focus on maintaining relationships, thus providing an opportunity to strengthen the social environment for PWSCI, which is a facilitator for their successful community reintegration (Barclay, Robins, Migliorini and Lalor, 2021)

2.6.5 Personal factors

Personal factors include age, gender, educational level, the individual's profession, employment, social background, the individual's coping styles, and the level and severity of injury, and they determine how an individual experiences disability and they influence community reintegration of PWSCI (Mohamad Hanapi, Zainin, Aziz and Darus, 2019). Literature highlights the role of these personal factor in decreasing functional independence, mobility, and social participation, resulting in decreased community reintegration (Babu et al., 2024; Mohan and Deb, 2024). Furthermore, PWSCI who failed to maintain their marriage after injury experienced a low QoL, had struggles in self-care, psychological issues, and overcoming physical barriers to mobility and accessibility to public spaces (Haque et al., 2021). Therefore, PWSCI struggled to participate in community activities, thus leading to poor community reintegration.

Life becomes difficult as PWSCI face psychological problems as they cope with the drastic changes in their life. These psychological problems often arise from various personal issues that are a result of the health condition (Zizzo, Gater, Hough and Ibrahim, 2022). PWSCI suffer from depression which is attributed to the realization of permanent functional deficits, loss of jobs, and sexual dysfunction that brings about uncertainty of life, fear, panic, loss of hope, and suicidal thoughts (Pilusa, Myezwa and Potterton, 2021). About 63% of PWSCI develop depression within the first 6 months of the injury as they strive to accept the new reality of life (Shin et al., 2012). With depression, an individual with SCI tends to have a reduced QoL and a significant decline in participation in community activities, thus achieving low community reintegration (Atobatele, Olaleye, Fatoye and Hamzat, 2018).

Socio-economic issues also influence how PWSCI experience life. SCI is largely associated with the loss of jobs and unemployment, thereby plunging them into poverty (Banks, Kuper and Polack, 2017). Research shows that most PWSCI struggle to find necessities as they are unable to find

money to support themselves or their families, resulting in poor QoL and low community reintegration (Reinhardt, Ballert, Brinkhof and Post, 2016).

2.7 Conclusion

This chapter has given an overview of SCI and discussed its epidemiology and outcome-based rehabilitation with a focus on community reintegration. Furthermore, the chapter has discussed factors that affect community reintegration at levels of body structure and functions, activity limitations, and participation restrictions while considering personal and environmental factors. Research in Malawi on community reintegration of PWSCI in Malawi is limited and there is a need for a study to explore their community reintegration and their life experiences in the community after hospital discharge.

CHAPTER 3: METHODOLOGY

3.1 Type of Study

This study was a qualitative descriptive study with a phenomenological approach. A phenomenological approach was selected for this study as it examines the human experience through descriptions provided by the participants (Alhazmi and Kaufmann, 2022). In this study, in-depth interviews were used to investigate the life experiences of PWSCI and their perceptions of community reintegration.

3.2 Source of subjects

Records of patients with spinal cord injury discharged from Kachere Rehabilitation Centre (KRC) and Queen Elizabeth Central Hospital's (QECH) were screened and patients who were at least 6 months post-hospital discharge were identified as suitable participants for the study. Screening was done in the month of July in 2023.

3.3 Sample Selection

A purposive sampling strategy was used to identify the potential participants based on the inclusion criteria below.

3.3.1 Inclusion Criteria

The following were the inclusion criteria for the study:

- Diagnosis of SCI, irrespective of the cause (traumatic or non-traumatic), type (paraplegia or tetraplegia), and completeness of the injury
- The patients with spinal cord injury who were more than 6 months discharged from KRC and QECH and residing in Blantyre
- Patients who were 18 years old and above
- Patients who gave a voluntary informed consent

3.3.2 Exclusion Criteria

All eligible participants who were readmitted back to the hospital during data collection were excluded from the study.

3.4 Sample Size

An estimated sample ranging between 15 and 25 participants was included in the study. The interviews were conducted on participants who were at least 6 months post-hospital until data saturation

was reached. Through the course of the interviewing process, the researcher observed that no new themes and ideas emerged after interviewing the tenth participant. However, three more participants were interviewed to confirm that data saturation was reached, and no new information emerged from the three interviews. This range was selected as it is optimal for data and 'meaning' saturation. Meaning saturation refers to the point when the issues investigated are fully understood and no further dimensions, nuances, or insights into issues can be found (Hennink, Kaiser and Marconi, 2017).

3.5 Instrumentation and Outcome Measures

The following instruments were used during data collection:

- Interview schedule (Appendix E)-PWSCI were asked questions relating to their personal life, their environment and occupation.
- Digital tape recorder

3.6 Procedure

3.6.1 Pilot Study

The researcher tested the interview questions by doing a minimum of three interviews with eligible participants. The participants were given an opportunity to ask any questions for clarity and they did not need any clarity of the questions. The interviews underwent the same data analysis as that in the main study. Thereafter, the data of the pilot test and the results were discussed with the supervisor to see if the answers to the questions addressed the aims of the study. It was determined that the answers to the questions had information that was answering the specific objectives of the study. This meant that the questions were addressing the aims of the study and no changes were made to them. Furthermore, the data of the pilot test were added to the main study for analysis together with the rest of the interviews.

3.6.2 Main Study

Permission was obtained from the directors of QECH and KRC to access files of patients with SCI discharged from the two hospitals (Appendices H and I). Patients with the diagnosis of spinal cord injury, discharged from the two institutions at least 6 months before the month of screening, aged 18 and above and were residing in Blantyre were identified and contacted telephonically. Nineteen participants were identified through the screening of patient records which was done in the month of July in 2023 at QECH and KRC and were called. Fourteen eligible participants voluntarily consented to be included in the study. One consenting participant was later admitted to KRC and was subsequently excluded from the study. The calls involved a brief explanation of the study, determining their exact location in Blantyre, as well as making appointments to meet them for the

interview if they give verbal consent. The participants provided the researcher with an address to their preferred location for the interview. The interviews took place from August 2023 to December 2023. On the day of the interview, each participant received an information sheet (Appendix A) and informed consent forms (Appendix C) to understand the study and provide a voluntarily signed consent to participate. After the informed consent was obtained, the demographic data of the participants were recorded by the researcher before the interviews. Participants had the option to decline to participate in the study despite the visit with no consequence to them. The individual face-to-face interviews were conducted using an interview schedule and the proceedings of the interview were recorded using an audio tape recorder.

The researcher is fluent in Chichewa, the main language used in Malawi, and English. The interview schedule was available in both languages. To produce the Chichewa interview schedule, forward translation of the interview schedule was done in which the original English interview schedule was translated into Chichewa by a bilingual translator. Thereafter, the backward translation of the Chichewa interview schedule to English was done by another translator who was familiar with the topic but was blinded to the original English interview schedule. Finally, the researcher compared the original and the new English interview schedules to check for any errors and inconsistencies to ensure that the questions had the same meaning. Therefore, each interview was conducted in any of these two languages based on each participant's preference. Before the interview, the researcher explained the aim of the study and what each question in the interview schedule intends to achieve about the aim of the study.

3.7 Ethical Considerations

The researcher received ethical approval from the University of Witwatersrand's Human Research Ethics Committee (HREC) (Appendix P) and the University of Malawi's College of Medicine Research Ethics Committee (COMREC) (Appendix O). Thereafter, permission from the directors of KRC and QECH for access to the patient records (Appendices H and I) to identify participants of the study was sought. Each participant was given the information sheet for them to understand the study before data collection and signed an informed consent form to participate in the study. The researcher ensured that the identity of the participants was kept confidential and the information obtained was used for the study, with pseudonyms used in the results section. Furthermore, any participant who decided to withdraw from the study was not penalized, and the cost implication of the study was upon the researcher, with no participant incurring any costs during the study.

The digital interview files and transcripts were stored in a password-protected folder on a password-protected computer and each file was named with a code to ensure the participants were not identified. Furthermore, all the printed materials such as interview transcripts, the signed informed consent forms and other documents used in the study were kept in a locked cabinet in a secure room at Kamuzu University of Health Sciences in Malawi and are accessible to the researcher only. The stored data will be kept for a minimum of 5 years after completion of the study.

3.8 Data Analysis

The recorded interview files were transferred and saved in a password-protected laptop. The files were coded to maintain privacy and confidentiality. Thereafter, they were transcribed verbatim by an external transcriber. For interviews conducted in the Chichewa language, the transcripts were translated into the English language by the transcriber and translated back to the original language by an independent translator to ensure that the meaning was maintained during translation. The data were analysed using thematic content analysis and during analysis, each transcript was read multiple times to familiarize with the content. Then, similar themes and thoughts were identified grouped and codes were generated inductively. The codes were grouped, and themes arose. Data from the demographic information tool were analysed descriptively using the Statistical Package for Social Sciences (SPSS) version 26 to determine mean, frequency and standard deviation for participant profiles.

To ensure the trustworthiness of the study, transcripts in Chichewa were translated to English language and then back to the original language. The researcher checked them and ensured that the translation did not change the meaning of the statements in the transcripts. During data analysis, the researcher, together with the supervisor, who is very experienced in qualitative data analysis and publication, each manually coded the first two transcripts separately. This was done to ensure that intercoder reliability was maintained before all transcripts were coded. Furthermore, participants who met the inclusion criteria were recruited in the study and were able to provide their experiences of living with SCI. These findings are presented in the next chapter.

3.9 Conclusion

This chapter has highlighted the methodological approaches of this study, including study type, source of participants, sample selection, inclusion criteria, exclusion criteria, the pilot test of the interview schedule, and the main study. It further gave details about the ethical considerations of the study and also details of data analysis.

CHAPTER 4: FINDINGS

4.1 Introduction

This chapter presents the study findings, beginning with a description of the demographic profiles and continues with the presentation of themes found under each study objective through the narrative approach and quotes are provided with pseudonyms.

4.2 Demographic profile

Thirteen participants consented and were included in this study. Nine of them were male, five were female, and they all had paraplegia. Their mean age was 38.1 years (SD 12.38). Their mean duration of living with SCI was 3.2 years (SD 1.21), with the mean length of hospital stay being 5.1 months (SD 2.40). Table 1 shows the full sociodemographic profile of the participants.

Table 1: Sociodemographic information

Pseudonym	Age	Sex	Diagnosis	Cause	Completeness	Years with SCI	LOS inpatient rehab (months)	Occupation before SCI	Occupation after SCI	Marital status before SCI	Marital status after SCI	Level of education
Alan	65	M	T8/9 Paraparesis, ASIA C	Fall from height	Incomplete	6	2	Security officer	unemployed	Married	Married	Primary (std 7)
Amelia	53	F	T10/11 paraparesis, ASIA C	Road traffic accident	incomplete	3	6	Primary school teacher	unemployed	Widow	Widow	Tertiary
Albert	23	M	T7/8 Paraparesis, ASIA D	Road traffic accident	Incomplete	3	5	Brick layer	unemployed	Single	Single	Primary (std 7)
Andy	42	M	T6/7 Paraparesis, ASIA B	Road traffic accident	Incomplete	4	4	Car dealer	No business	Married	Married	Tertiary
Adrian	43	M	T9/10 Paraplegia, ASIA A	Road traffic accident	Complete	3	4	Shop owner	No business	Married	Married	Primary (std 3)
Adam	38	M	T12/L1 Paraplegia, ASIA A	Road traffic accident	Complete	3	3	Plumber	unemployed	Married	Married	Tertiary
Arnold	25	M	T12/L1 Paraplegia, ASIA B	Road traffic accident	Incomplete	2	4	Brick laying	unemployed	Single	Single	Secondary (form 4)
Abigail	42	F	T8/9 Paraparesis, ASIA D	Fall from a height	Incomplete	5	8	Business	No business	Married	Divorced	Primary (std 6)
Aiden	36	M	T7/8 Paraparesis, ASIA D	Assault	Incomplete	2	5	Primary school teacher	Primary school teacher	Single	Single	Tertiary
Angel	46	M	T9/10 Paraparesis, ASIA D	Road traffic accident	Incomplete	3	5	Agro dealer	No business	Married	Married	Secondary
Adonis	27	F	T4/5 paraparesis, ASIA C	Assault	Incomplete	2	8	mechanic	unemployed	Married	Married	Secondary
Abel	31	M	T11/12 Paraparesis , ASIA C	Road traffic accident	Incomplete	3	2	Shop keeper	unemployed	Married	Married	Tertiary
Anna	24	F	T7/8 Paraparesis, ASIA D	Road traffic accident	Incomplete	2	10	business	No business	Single	Single	Primary

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¹ ASIA means American Spinal Association (ASIA) Impairment Scale

² LOS means Length of hospital stay

This study aimed to explore the life experiences and perceived community reintegration of PWSCI, and the findings will be reported as per the three objectives stated in section 1.4.1.

4.3 Objective one: Exploring the challenges facing PWSCI post-hospital discharge

Five themes emerged when exploring the challenges faced by PWSCI. These themes included challenges relating to the experience of limited participation in the community, the experience of vocational problems, the presence of SHCs, lack of resources and environmental problems, as shown in Figure 1 below:

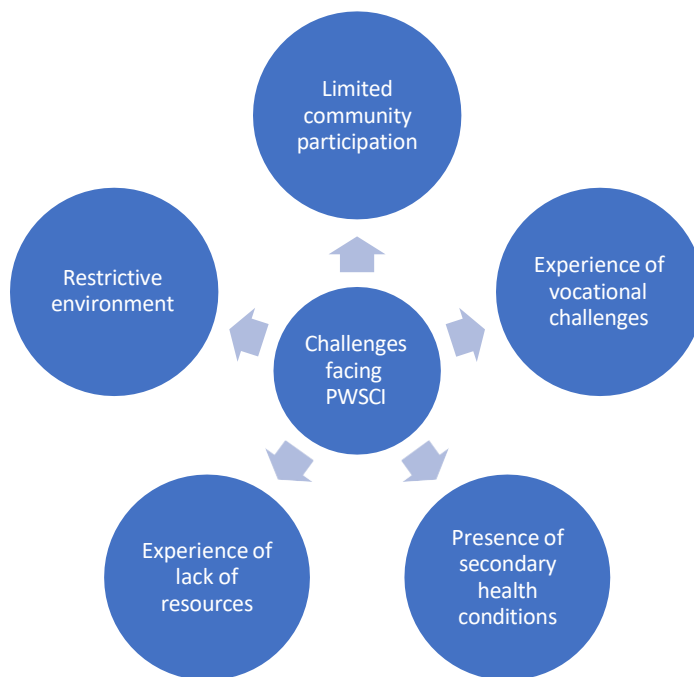


Figure 4.1: Themes relating to challenges facing PWSCI

4.3.1 Theme one: Limited community participation

Most participants reported having difficulties in participating in their homes and their community, citing several reasons. Some of them reported uneven and sloped terrain as the main cause of their mobility problems:

I fail to move freely in this village... If the road was okay [not hilly], I would have been reaching the main road... it is far to watch football matches and you know how our road is. (Arnold, 25 years old, 2 years living with SCI).

It isn't easy to move around here. You can see it's a rough, uneven surface outside the

house and a big gully behind the house. During the rainy season, water overflows and sometimes it reaches the house. (Abigail, 42 years old, 5 years living with SCI)

They further lamented their inability to move around the home and community because of damaged and worn-out mobility equipment.

Moving is difficult because of the [damaged] wheelchair. (Arnold, 25 years old, 2 years living with SCI)

About my walking sticks, only one of them is good, and the other stick has its rubber base worn out...This makes walking difficult out there. (Abigail, 42 years old, 5 years living with SCI)

Furthermore, some participants felt that they were not adequately prepared for discharge from the hospital and that it contributed to their limited participation in home and community activities.

We were just surprised we were being discharged when I was not trained to go to the toilet to urinate or poop[sic]. (Adam, 38 years old, 3 years living with SCI)

I did not feel good when they were discharging me unexpectedly ... I was expecting that I would be walking by the time I was discharged from the hospital, just like others. (Abel, 31 years old, 3 years living with SCI)

Sustaining SCI resulted in a significant change in the life of participants as most of them reported being unable to perform daily activities such as bathing, grooming, and dressing.

When it comes to bathing and let's say there is no water, I cannot manage to carry the water bucket to go with it to the bathroom to bath. Those are some of the problems. (Andy, 42 years old, 4 years living with SCI).

It is more difficult for me to wear underwear than a dress, skirt, and a blouse, but I find it challenging to dress. (Angel, 46 years old, 3 years living with SCI)

4.3.2 Theme two: Experience of vocational challenges

Most participants reported facing an uphill challenge to return to work since returning home after

hospital discharge.

Some things require me to bend, kneel, or go under the car, which cannot work now. . (Andy, 42 years old, 4 years living with SCI)

Sometimes, I used to do piecework because I am a builder, but I just stayed since the injury happened. It is no longer happening, and I am always broke...I have no money at all. (Arnold, 25 years old, 2 years living with SCI)

The burden of the SCI was felt even more as some of the participants reported a loss of their jobs because they could no longer perform their tasks after hospital discharge. Thus, the injury meant an end to their jobs.

They never told me at work that I was fired; they just left me out of the payroll without notice, and that was it. (Andy, 42 years old, 4 years living with SCI)

I used to work as a Health Surveillance Assistant focusing on TB...I stopped doing all that [after returning home from hospital]. (Adrian, 43 years old, 3 years living with SCI).

Life has changed because now I cannot work anymore... As a teacher, I cannot effectively work because I lost my hand function and I never returned to my workstation since I returned home. (Aiden, 36 years old, 2 years living with SCI)

Participants who were entrepreneurs before SCI lost their businesses after returning from the hospital. They attributed this to their inability to meet the demands to maintain their businesses.

I used to own a grocery shop where I used to sell various things. Right now, I cannot point at anything that I used to do that was giving me income. (Adrian, 43 years old, 3 years living with SCI)

Before I got injured, I was reliable in plumbing work, and I used to win contracts and work. But now all those things stopped. (Adam, 38 years old, 3 years living with SCI)

I was doing business before my injury by selling shoes... At the same time, I was an automobile mechanic. I am not able to do any of those things after returning home from hospital. (Adonis, 27 years old, 2 years living with SCI)

4.3.3 Theme three: Presence of secondary health conditions

Participants experienced different kinds of health problems ranging from physical health challenges to psychosocial health challenges. Most participants reported experiencing persistent pain, which some accepted as part of their life since being discharged from the hospital and reported that it makes their life difficult as they live in their homes and community.

I feel a lot of pain in my legs... right now, I am having general body pains. It feels like I have a dislocation in the legs, and the pain is constantly present, which makes my life difficult (Arnold, 25 years old, 2 years living with SCI)

For me, to walk around [the home and the community] is difficult with the pain I feel. This pain is not stopping; it's still there. (Adrian, 43 years old, 3 years living with SCI)

The pain in my back comes with a severe burning sensation and numbness. I also feel pain in my chest, stomach, and my legs. This problem makes me suffer always. I can't move around because of this (Angel, 46 years old, 3 years living with SCI)

Some participants also experienced persistent pressure sores, which were painful and debilitating.

I also developed sores. They initially healed, but they have developed again ever since I got discharged, and the one I have now seems to be persistent...I often fail to visit other people because of the way things are now. (Arnold, 25 years old, 2 years living with SCI)

Furthermore, most participants expressed worry over the sexual problems they experienced as married people. They indicated that life was not the same since they were discharged from the hospital as they could not perform their sexual duties with their spouses as they experienced erectile problems. This led to rising tension with

their spouses. Some reported being ridiculed by their spouses because they failed to perform during sexual intercourse.

There are some issues in a family that happen in marriage as man and woman...I feel like those issues were not addressed at the hospital in terms of how we will be living like husband and wife...How will I manage with this tube [catheter]? (Andy, 42 years old, 4 years living with SCI)

To tell the truth, my life with my wife changed as married people...nothing happens between us as a man and a woman who are married. (Adrian, 43 years old, 3 years living with SCI)

When it comes to my marriage with my wife, we do not understand each other when it comes to living as a man and his wife because of how I am now...With the urine just coming out, I can't manage to be the man she needs...my wife used to say we are just living like we are two women in the house. (Adam, 38 years old, 3 years living with SCI)

Participants experienced bladder incontinence, leading to feelings of embarrassment and subsequent prolonged isolation.

Another problem is that when urine comes out, it just comes out anyhow to the point that when you are around people, it feels so embarrassing. This makes me just stay home sometimes. (Adam 38 years old, 3 years living with SCI)

I cannot hold up urine whenever I start feeling the urge to urinate. It's always late. I cannot stay around a group of people without bearing in mind I have this problem. I get embarrassed. (Angel, 46 years old, 3 years living with SCI)

Others pointed out that they chose to stay away from people because they felt ashamed of their health condition, such that they did not like going out of their homes.

Ever since I came from the hospital, I have never gone to anyone's house. I just feel like they will be talking about me every time I go out to someplace. (Andy, 42 years old, 4 years living with SCI)

I do not go outside the house because if I go out and sit there, the neighbors will stop whatever they are doing and start looking at me. (Adrian, 43 years old, 3 years living with SCI)

Most participants reported experiencing psychosocial problems such as depression, reduced happiness, frustration, and shame attributed to loss of income, physical limitations and divorce.

The things that I was able to do now I fail to do, like going to play football and other work that involves my legs. It is frustrating, but I just accepted it. (Arnold, 25 years old, 2 years living with SCI)

It's frustrating because now I eat things that I am not supposed to eat...eating vegetables every day...When I was able to make money, I could eat whatever I wanted anytime. (Adrian, 43 years old, 3 years living with SCI)

My husband was leaving me home for other women for several days, and it was quite depressing for me...This continued for several months until he was gone for good. I just chose to spend weeks at home without going out to friends and church. (Abigail, 42 years old, 5 years living with SCI)

4.3.4 Theme four: Experience of lack of resources

The study found that most participants experienced a lack of resources such as training equipment and necessities like food, which they attributed to their inability to generate income, which would otherwise help them to buy some of these resources.

Here, I lack equipment that I could use for training like the way it is there...I think I would have had a huge change if I was still at the hospital. (Arnold, 25 years old, 2 years living with SCI)

[Lack of] food is the main problem we are facing, even my body lost some weight....if I had not lost my business, these issues wouldn't have been there. (Adrian, 43 years old, 3 years living with SCI)

For participants who were breadwinners, their main concern was a lack of money, which resulted in their inability to provide for their family members and led to more worries.

I am the breadwinner in this house, and I must pay school fees for my girls, but I can't...there is no money. I am passing through a big burden. (Amelia, 53 years old, 3 years living with SCI)

I fail to take care of my children for them to go to school. Since the time I returned home, they were sent back home due to lack of fees...I don't know where to get the money. (Angel, 46 years old, 3 years living with SCI)

4.3.5 Theme five: Restrictive environment

Most participants lamented the lack of environmental modifications to suit their ability to use the environment easily. This resulted in the environment becoming a barrier to moving freely in their homes and in accessing some of the important public places such as worship centres.

This wheelchair does not fit through the doors of the bedroom. I drag myself onto the floor, and then I get out of the house to sit on it on the veranda. (Adam, 38 years old, 3 years living with SCI)

Sometimes, I just prefer staying indoors because the surroundings are not good for me to move around with the wheelchair freely. (Adonis, 27 years old, 2 years living with SCI)

Abigail, on the other hand, reported that she stopped going to church because the church premises were not accessible because of the way they were constructed, leading to reduced social interactions with fellow church members.

I stopped going to church after I got discharged from Kachere...with the way the church was constructed, I could not climb the stairs easily. (Abigail, 42 years old, 5 years living with SCI)

Other participants developed a fear of moving into their community because of their unfavorable social environment where people talked badly about them. For example, Adrian attributed his challenges with mobility to negative societal attitudes.

People talk bad about me...So when I see someone not doing their stuff, that means they are focusing on me, and I just choose to stay indoors. (Adrian, 43 years old, 3 years living with SCI).

4.4 Objective two: Inquiring about the coping strategies used by people with spinal cord injury

This study found that participants used different coping strategies to successfully live life in their homes and community. Four themes emerged from the analysis and are shown in Figure 2 below.

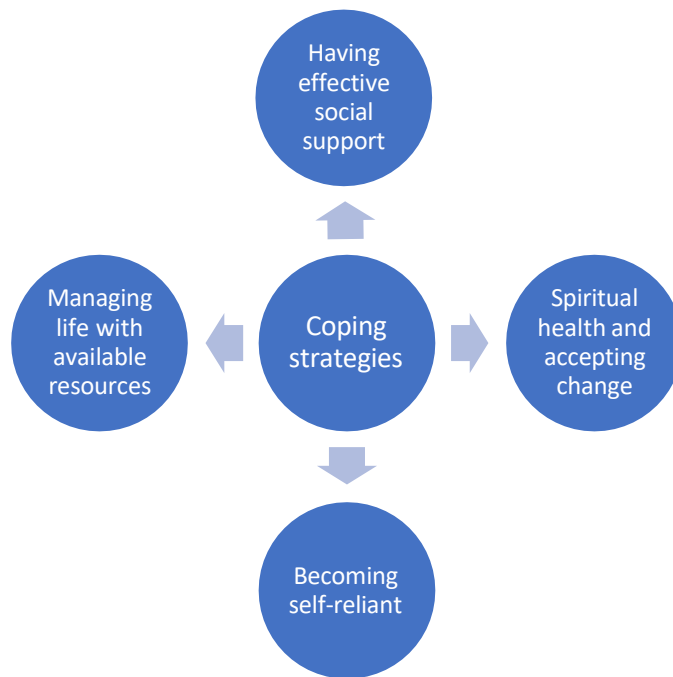


Figure 4.2: Themes of coping strategies employed by people with spinal cord injury

4.4.1 Theme one: Having effective social support

Most participants depended on the well-organized social support system, and they gave credit to their spouses and other family members for their unwavering support in providing care for them and an emotional pillar of support in facing life with its challenges.

My life is better because I have a good relationship with my wife...When I am down, she encourages me. (Andy, 42 years old, 4 years living with SCI)

I am receiving enough care from my wife. Our marriage was 4 months old when I got injured, but she never left me and now years have passed. (Adrian)

Most importantly, I should thank my wife, who has taken care of me from the beginning. (Adonis, 27 years old, 2 years living with SCI)

Other participants further commended members of her church and community for being crucial in their quest to settle back into the community and for providing them with food and other items that helped them live happy lives despite facing several health challenges.

When I came back from the hospital, the church members helped me a lot to settle. They brought me things like maize flour, soap and other foodstuffs...they do this even now and I feel good because they give me the things I need. (Abigail, 42 years old, 5 years living with SCI)

The people in this community are amazing. They always visit me frequently and bring me groceries and everything I need. I didn't suffer when I returned home from the hospital. (Amelia, 53 years old, 3 years living with SCI)

4.4.2 Theme two: Spiritual health and accepting change

Most participants felt that in accepting the situation they were in, there was a need to recognize and trust the higher powers or deities to provide them with good health. In doing so, they were infused with hope for a good life in the face of many challenges.

With encouragement from my wife, we had time to pray for improvement ...we had faith that things would be better. When I removed the catheter, urine had stopped coming out anyhow, and I stopped using it completely. (Andy, 42 years old, 4 years living with SCI)

I left everything in God's hands, and I am satisfied. I am certain one day I will walk again, even though some people think it is impossible. (Adrian, 43 years old, 3 years living with SCI)

Furthermore, these participants live happily due to their ability to accept the change that came into their lives because of SCI, and that improved their psychological health as participants reported finding peace by accepting the situation they were in when they returned from the hospital.

That is when I started finding peace in my heart and that I should accept the situation I am in. (Andy, 42 years old, 4 years living with SCI)

When I felt that life was useless, it dawned on me that I had a lot of things to thank God for...I decided to leave things as they were and accept the reality. I have never worried about life ever since. (Arnold, 25 years old, 2 years living with SCI)

4.4.3 Theme three: Becoming self-reliant

Some participants indicated that by becoming self-reliant, they were able to cope with the challenges that came with SCI after hospital discharge. Participants were involved in farming and business activities to generate income with which to use to improve their life.

We have a vegetable garden here... when rains come, we plant maize, cassava, and vegetables...we plant on our own. (Andy, 42 years old, 4 years living with SCI)

Together with my wife, we opened a small business. We sell clothes and we use the money to support our daily life, as you can see. (Adrian)

I saw that this is not the end of everything, but I can fix something that can help me. That is when I started a business, and it started growing until we met some circumstances which made the business drop. (Adam, 43 years old, 3 years living with SCI)

Participants also used their functional abilities to do self-care activities, other than waiting for spouses and guardians to take care of them, as well as taking the initiative to fix their mobility equipment when faulty.

For the sores to heal, I sometimes wash them with warm salt water; then, I apply medication until it dries up. (Arnold, 25 years old, 2 years living with SCI)

When my wheelchair gets damaged, I sometimes fix it myself. (Adonis, 27 years old, 2 years living with SCI)

4.4.4 Theme four: Managing life with available resources

Most participants reported that in facing challenges at home, they learned to improvise. With the loss of function related to SCI, most participants could not manage to run their errands effectively and turned to using other means to save their businesses from collapsing. They reported that they involve other people around them to run businesses or use communication devices to ensure business processes run smoothly, even though they risk losing money if they use untrustworthy individuals.

90% of my life, I depend on people to do things for me... I talk to someone to help me if I want something to happen. I usually send someone to get things done when it's about business (Andy, 42 years old, 4 years living with SCI)

To cope with psychological challenges, participants reported that they spent time with family members and friends. In doing so, they reported that it relieved their stress.

Now, I can go and chat with people, but at that time, I was just staying in the house like the time I was just sleeping. It felt so heavy for me. (Adam, 38 years old, 3 years living with SCI)

When a group of my friends comes to chat with me, I get relieved of my stress, but when they are gone, the stress comes back. (Abigail, 42 years old, 5 years living with SCI)

4.5 Objective three: Seeking suggestions to further community reintegration of PWSCI

Two themes relating to suggestions emerged from the findings. The two themes are shown in Figure 3 below:



Figure 4.3: Themes on suggestions to further improve the community reintegration of PWSCI

4.5.1 Theme one: Community proactiveness in environmental modification

Participants suggested that community members should be proactive in bringing environmental modifications to improve the accessibility of community resources to PWSCI. They suggested that roads should be made in a disability-friendly way to allow them to move freely and easily in the community.

I fail to move freely in this village...the main issue being the roads. If the road was okay, I would have been reaching the main road, but there are no such projects for this. (Arnold, 25 years old, 2 years living with SCI)

Other participants suggested that community members and other stakeholders should ensure that some essential community resources such as water and electricity should be brought closer to the homes of PWSCI to ensure ease of access and improve their lives in the process.

Water is very important. It should be brought near to my home because water is for daily use. I take three days without bathing sometimes because no one is there to fetch it for me. (Abigail, 42 years old, 5 years living with SCI)

4.5.2 Theme two: Effective preparedness of PWSCI for home

This study found that most participants expressed dissatisfaction with their untimely discharge from the hospital and felt that it contributed to their poor functional outcomes at home. Thus, most participants suggested that health professionals should be proactive in preparing them for home by giving timely communication of the plan leading to their discharge from the hospital.

They should tell a person that they are getting discharged 10-15 days before that on this certain day we will discharge you so that the person should prepare properly. (Andy, 42 years old, 4 years living with SCI)

They should not be discharging a person early because some are discharged by force. It shouldn't feel like they are being chased from the hospital. They should prepare the patients well and communicate early. (Arnold, 25 years old, 2 years living with SCI)

They should be informing patients about their discharge in advance, like a month prior. Sometimes, it's difficult to accept that you're being discharged. (Adonis, 27 years old, 2 years living with SCI)

Participants further suggested that in the process of preparing them for home, health professionals should take the initiative in training and equip them with skills for mobility, self-care, and sexual life.

At least when one is going home, it is good to teach them how to propel a wheelchair and, if broken, how to fix it.... I was never trained in those skills, and they just told me to leave. (Andy, 42 years old, 4 years living with SCI)

Health workers should prepare the patients with skills on how to face life after they are discharged...things like sexual life skills and how to prevent sores because if they are not

addressed, they can destroy one's life. (Adam, 38 years old, 3 years living with SCI)

Some participants went further to suggest that healthcare institutions, individuals, and community members should have initiatives aimed at providing business capital for PWSCI in preparation for life at home. They felt that such an initiative could provide them with a starting point for their livelihood and could consequently improve their QoL as they would be able to afford necessities in their life after the hospital.

When discharging us, there must be a fund aimed at raising capital for any business at home. That would be helpful to know where to start from when at home. (Adrian, 43 years old, 3 years living with SCI)

Helping us with business capital so that my wife can run a business to earn a living. This would be a welcome development for us. (Adonis, 27 years old, 2 years living with SCI)

4.6 Conclusion

In this chapter, the results of the current study have been presented. From the interviews, five themes emerged on the challenges facing the PWSCI. This study also explored the coping strategies used by PWSCI to mitigate against the challenges they face, and four themes emerged. Finally, two themes emerged as suggestions of PWSCI on ways to further improve their community reintegration.

CHAPTER 5: DISCUSSION

5.1 Introduction

In this chapter the results of the current study will be discussed. This study aimed to explore PWSCI's challenges after hospital discharge, their coping strategies as they live in their community, and suggestions to further their community reintegration. The results will be compared to with literature in the areas of life experiences and community reintegration of people with spinal cord injury. The discussion will further highlight the clinical implications of results of this current study.

5.2 Demographic profile

The demographic findings of this study suggest that SCI affects middle-aged adults, with men more affected than women, similar to the literature (Safdarian et al., 2023). The majority of participants in the current study sustained SCI due to road traffic accidents, followed by assault and falls, concurring with the literature (Chokotho et al., 2022). Furthermore, the demographic findings of the current study suggest high unemployment levels among PWSCI after hospital discharge, which is supported by the literature (Post et al., 2020; Bezuidenhout et al., 2023). The demographic findings highlight the need for initiatives to prevent injuries through policy interventions and sensitization at community level.

5.3 Challenges facing people with spinal cord injury

People with spinal cord injury in the current study experienced many challenges including limited community participation, vocational challenges, presence of secondary health conditions, lack of resources and restrictive environment.

5.3.1 Limited community participation

The limited participation reported in by PWSCI in the current study were due to several factors. Predominantly, PWSCI in this study experienced functional challenges and reduced mobility. This finding is supported by Du Plessis et al. (2018) who found that PWSCI had deteriorated physical function, which affected their mobility in the community after being discharged from the hospital. The reduced mobility further leads to unmet needs of reduced social participation in areas of access to counseling centres, health facilities, and education facilities (Tijm, Cornielje and Edusei Kwaku, 2011; de Serres-Lafontaine et al., 2023). This consequently leads to unsuccessful community reintegration of PWSCI who become unable to functionally cope with the demands of life in the

community.

The study further established that poorly designed wheelchairs increased the difficulty of achieving mobility in the community with few environmental modifications for the successful use of the wheelchairs, concurring with the literature (de Serres-Lafontaine et al., 2023; Mohan and Deb, 2024). This is a common problem in low and middle- income countries where an interplay of environmental barriers and inappropriately designed assistive devices and technologies results in reduced mobility in the community and social participation of PWSCI (de Serres-Lafontaine et al., 2023).

The findings of the current study highlight the need for improvement in rehabilitation of PWSCI to improve the eventual community reintegration of PWSCI after discharge. Rehabilitation professionals in clinical settings should consider the environment before discharging PWSCI (Mukaino et al., 2020). They should ensure a proper home environment assessment is done to facilitate the choice of appropriate wheelchair and mobility designs for PWSCI. Furthermore, rehabilitation professionals can facilitate the initiative of making environmental adaptations together with caregivers and community members to improve patients' freedom of movement (Norin et al., 2017; Rahman, 2018). Some of the environmental adaptations may include erecting ramps, widening doors, levelling the local road networks and advocating for non-slip surfaces, and these adaptations are crucial for improving mobility and community participation of PWSCI (Rahman, 2018). Before discharge, PWSCI can also be equipped with skills to overcome minor challenges such as inflation of wheels and repairing of minor damages to the wheelchairs. By doing so, PWSCI may become less reliant on the health system and become more independent.

5.3.2 Experience of vocational challenges

The study also found that PWSCI suffer from vocational challenges where they lost their jobs or did not get employed after hospital discharge. This finding concurs with the literature, which found that employment levels and earnings decrease among PWSCI (Jaffe et al., 2024). Finding and maintaining employment is challenging among PWSCI and results in poor QoL, low life satisfaction, and reduced social participation, plunging them into various mental health problems such as depression and substance abuse (Goetz et al., 2018). Conversely, PWSCI who are employed have high levels of life satisfaction and better mental health outcomes in areas such as high self-esteem, motivation and positive coping, sexual life, and ADLs (Goetz et al., 2018; Jørgensen, Hedgren, Sundelin and Lexell, 2021). Furthermore, PWSCI who are employed or can return to work have many opportunities for social interaction, which enhances their social participation and community

reintegration as they can form healthy relationships and networks, which are key to healthy living (Leiulfsrud et al., 2020). Unfortunately, most of the PWSCI in this study were either unemployed or had little to no income due to reduced clientele, leading to a one-sided perspective where return to work is concerned.

The findings of this study emphasize that many factors influence how PWSCI struggle to maintain their employment, to find new employment, or to start some income-generating activities. These factors may include negative societal attitudes toward PWSCI, inadequate vocational support during rehabilitation, environmental barriers and psychosocial barriers (Karcz et al., 2022; Bezuidenhout et al., 2023). All stakeholders should be involved in overcoming the vocational challenges PWSCI face to achieve a good QoL. Policymakers can play an important role in making and enforcing policies aimed at improving the livelihood status of PWSCI, while rehabilitation teams can put in place vocational programs to prepare them for re-employment, job creation, or employment of PWSCI. Vocational rehabilitation during hospital admission is key to a successful return to work, employment, or job creation and is an important component of rehabilitation for successful community reintegration of the PWSCI (Kee et al., 2020). PWSCI can also become proactive in searching for employment opportunities while also taking initiatives to create income-generating activities.

In Malawi, vocational rehabilitation to prepare PWSCI for life after hospital is not effective. This ineffectiveness may be attributed to the lack of post-hospital discharge planning (Ranjbar Hameghavandi et al., 2024). Furthermore, a shortage of human resources in the rehabilitation institutions may also be a contributing factor. Few occupational therapists are employed at Kachere Rehabilitation Centre for all the patients, and it is possible that not all patients would receive adequate vocational care because of the shortage of staff. Another reason could be the limited length of hospital stay allocated to patients for rehabilitation, leading to health professionals starting to focus on body functional outcomes only and not on other important areas of rehabilitation, such as vocational training. In the end, PWSCI are discharged from hospitals, clueless about ways of earning and getting employment opportunities. To deal with the ineffective vocational rehabilitation, physiotherapists can team up with occupational therapists and social workers to set physical rehabilitation goals in line with readiness for work (Ottomanelli, Barnett, Goetz and Toscano, 2015). In doing so, physiotherapists can tailor the physical tasks for the PWSCI to be employment-related, hence preparing the PWSCI for life after discharge.

Although current rehabilitation practices in Malawi do not expand beyond addressing physical

function, the current study's findings highlight the need for rehabilitation programs to incorporate entrepreneurship training for PWSCI before discharge. Through the incorporation of entrepreneurship in rehabilitation programs, PWSCI will be empowered to become financially independent and be able to support their life effectively, hence improved community reintegration.

5.3.3 Presence of secondary health conditions

The challenges of SHCs experienced by PWSCI in this study included chronic pain, sexual dysfunction, bladder and bowel dysfunction, pressure sores, and depression, as supported by a South African study by Pilusa, Myezwa and Potterton (2021).

Of note is the experience of pain among PWSCI in this study, which concurred with recent study findings. Mashola, Korkie and Mothabeng (2024) explored the experience of pain among PWSCI who described it as “worse than the direct consequences of SCI,” “constantly lurks,” and “restrictive.” In this current study, PWSCI had a similar description of pain as “not stopping, it’s still there.” This suggests that pain is always present, an experience that significantly reduces their participation in activities in various public places, thereby reducing their community reintegration. The experience of pain among PWSCI is common and there is a need for collective effort among health professionals to find ways of improving the health of PWSCI by enforcing the use of effective pain management methods to promote participation in various community activities, thereby improving community reintegration (Franz et al., 2019).

Furthermore, the current study's findings on pain informs the health professionals in clinical settings of the importance of preparing PWSCI on various aspects of pain before discharge. Before discharge, rehabilitation professionals should educate PWSCI on the different types of pain and its causes such as faulty posture, pressure injuries and prolonged positions (Widerström-Noga et al., 2023). Furthermore, PWSCI should be equipped with pain self-management skills such as range of motion exercises, massage, relaxation techniques, heat and cold therapy and breathing exercises (Guy et al., 2016). The presence of severe pain reduces the community reintegration of PWSCI, highlighting the need to incorporate pain management in inpatient rehabilitation of PWSCI to improve community reintegration outcomes (Henderson and Mashola, 2024).

Furthermore, the study findings of SHCs such as bowel and bladder dysfunction, pressure sores and depression concur with the literature (Mota, Ribeiro and Barbosa, 2016). These SHCs predominantly result in reduced mobility and social isolation among PWSCI as they choose to avoid

public places due to the sense of embarrassment associated with these SHCs, similar to the available literature (Braaf, Lennox, Nunn and Gabbe, 2017; Atobatele, Olaleye, Fatoye and Hamzat, 2018; Mahooti, Raheb, Alipour and Hatamizadeh, 2020). This social isolation acts as a barrier to social participation and this significantly decreases the PWSCI's QoL and community reintegration (Cimino et al., 2024).

The impact of these SHCs highlights the need to address them comprehensively. Health professionals need to promote practices aimed at improving bladder and bowel management to subsequently increase social participation. The prevention of pressure sores should also be a priority area for health professionals, caregivers, and the PWSCI as they are difficult to treat and significantly reduce the QoL of PWSCI (Mervis and Phillips, 2019; Vecin and Gater, 2022). Their direct link with mental health problems such as shame, embarrassment, and depression among PWSCI highlights a need to effectively manage them to promote their social participation, QoL, and community reintegration (Piatt et al., 2016; Pilusa, Myezwa and Potterton, 2021). Furthermore, mental health care can be key to addressing the negative effects of depression and other psychosocial problems to facilitate community reintegration (Schultz, Mona and Cameron, 2022).

Notably, there is a close relationship between bladder and bowel dysfunction and sexual dysfunction. Literature shows that PSWCI who reported having bowel and bladder problems also had sexual dysfunction (Park et al., 2017). The current study found that some PWSCI associated their sexual problems with the discomfort that comes with the uncontrollable passing of urine or the presence of indwelling catheters. Rehabilitation must comprehensively address the issue of bowel and bladder dysfunction and sexual dysfunction by incorporating programs that educate PWSCI on ways of managing catheters to optimize their sexual life (O. E. C. Barrett, A. K. Ho and K. A. Finlay, 2022; Mahler et al., 2024). Sexuality is an integral part of a human being but it is disrupted in PWSCI (Angel and Kroll, 2020). A multidisciplinary team approach should be adopted during rehabilitation to ensure the sexual needs of PWSCI are met, even though most health professionals often feel embarrassed, lacking specialist skills and resources to address the issue of sexuality among PWSCI (Olivia EC Barrett, Aileen K Ho and Katherine A Finlay, 2022).

5.3.4 Experience of lack of resources

The findings of this study on the lack of resources highlight the challenges that PWSCI in low and middle-income countries experience (Darain and Arsh, 2019). The current study found that they struggle to access equipment and technologies that would otherwise facilitate their successful community reintegration. The finding of the current study agrees with literature which shows that

PWSCI often lack assistive devices such as appropriate wheelchairs, crutches, walking sticks, and other technologies, leaving them struggling to participate in social, recreational, and vocational activities, all of which are crucial for improving their QoL and successful community reintegration (Lofvenmark, Norrbrink, Nilsson Wikmar and Lofgren, 2016; Matter et al., 2016; Ahmed, Quadir, Rahman and Alamgir, 2018; Jeawon et al., 2023). The situation is different in high-income countries where PWSCI have good access to assistive devices to facilitate their function (Wäckerlin, Gemperli, Sigrist-Nix and Arnet, 2020).

Like in other low and middle-income countries, access to appropriate assistive devices such as wheelchairs and other mobility aids is limited in Malawi due to poverty (Oderud, 2014). Poverty prevents PWSCI to access better and appropriate assistive devices for mobility, self-care and others, leading to reduced participation in activities of daily living and community activities (Akter et al., 2019). This lack of access to appropriate assistive devices is compounded by the financial problems experienced by PWSCI, thereby forcing them to use equipment that is not designed to work in their challenging environment or not meet their requirements, mainly because of a lack of access to the right assistive devices and technologies (McSweeney and Gowran, 2019; Karki, Rushton, Bhattarai and De Witte, 2023).

The current study's findings on lack of resources underscore the need for rehabilitation teams to encourage governmental and non-governmental (NGOs) policymakers in Malawi to support PWSCI and help them to achieve successful community reintegration (Arejan et al., 2022). Non-governmental organisations can partner with rehabilitation teams to roll out programs such as community-based rehabilitation which, among others, aims at empowering local community members to mobilise resources to support PWSCI in their quest to achieve successful community reintegration (Trafford et al., 2021). Furthermore, government and NGOs should facilitate rehabilitation workshops for maintenance of assistive devices and also establishing local production and assembly units for assistive devices such as wheelchairs (Arejan et al., 2022). By doing so, the accessibility of assistive devices to PWSCI can be improved. However, care must be exercised when making the assistive devices accessible to PWSCI as they must meet the basic standards and their design should be appropriate to meet the needs of the PWSCI (McSweeney and Gowran, 2019).

5.3.5 Restrictive environment

The environmental challenges experienced by participants in this study, which included poorly designed buildings and hilly and uneven terrain, affected their accessibility in public places such as

churches, shops and other community facilities. This finding is similar to the finding of de Serres-Lafontaine et al. (2023) whose Tanzanian study found that PWSCI experienced barriers to accessibility to public places and buildings that had uneven entrances, narrow doors and no ramps, limiting their access to shops, medical facilities and other important government offices. The Tanzanian context is similar to Malawi where the majority of buildings and public places lack features that promote accessibility to various facilities and services for PWSCI. The restrictive environment in the context of Tanzania and Malawi may be attributed to a lack of enforcement of building regulations by authorities, leading to sub-standard, disability-unfriendly buildings and public places. If the environment is not conducive for PWSCI to use wheelchairs and other adaptive equipment for mobility, it limits their participation in various activities, leading to low community reintegration (de Serres-Lafontaine et al., 2023). The limited participation may be compounded by poor designs of wheelchairs and other adaptive mobility equipment which are common in the LMICs such as Malawi (Ekiz, Demir and Özgirgin, 2014).

These environmental barriers in low and middle-income countries are similar to those in high-income countries. In Finland, PWSCI experienced a lack of accessibility to public places and this affected their participation, leading to reduced community reintegration (Saarimäki et al., 2024). Additionally, Saarimäki et al. (2024) reported that PWSCI experienced a negative social environment which decreased their social participation. The same was reported by a study in China in which negative social attitudes from colleagues, friends, family and relatives resulted in problems in forming intimate relationships, using public places and participating in recreational activities among PWSCI (Yang et al., 2023).

A collective effort may be key to reducing the challenges posed by the environmental barriers faced by PWSCI in Malawi. The political will of the country can enhance the community reintegration of PWSCI by enforcing the laws and regulations related to the construction of public places and buildings in efforts to promote accessibility to these places by PWSCI (de Serres-Lafontaine et al., 2023; Kapsalis, Nils and Hale, 2024). Rehabilitation teams may also be involved in environmental modification in collaboration with community members. This may reduce some of the challenges PWSCI face and improve their community reintegration.

5.4 Coping strategies used by PWSCI to mitigate against the challenges they face

This study explored the coping strategies PWSCI use as they live in their communities and findings included staying spiritually or religiously healthy, accepting the injury situation and change, becoming self-reliant, and managing life with available resources. These findings concur with the

literature (Babamohamadi, Negarandeh and Dehghan-Nayeri, 2011; Byra and Gabryś, 2022)

5.4.1 Having an effective social support

Having an effective social support system highlights the importance of family members, friends, colleagues, peer groups and community members in the life of

PWSCI. Social support, especially from family members and peer groups, plays an integral part in promoting the emotional well-being of PWSCI (Ghannad, Fateminik and Allipour, 2018). Peer support groups also form a very important part of an effective support system. However, PWSCI in this study did not attribute any coping strategies related to peer groups. This may be due to a lack of awareness of the existence of peer support groups, no peer groups existed, or that family support was enough for emotional support and did not see the need for peer support groups. However, there is a need for stakeholders to collaborate in the formation of peer support groups to ensure improved functional, emotional and social outcomes of PWSCI (Gupta, Jaiswal, Norman and DePaul, 2019). Most of the studies on the effectiveness of peer support groups for PWSCI were done in United States of America and other high-income countries where resources and funding are readily available, and also the healthcare context is different from low-income countries .

In settings where network facilities are in good, video conferencing can be used for peer group meetings (Barclay and Lalor, 2022). However, in Malawian communities, where network problems are common, using such platforms and other technologies may prove to be challenging.

5.4.2 Spiritual health and accepting change

Most PWSCI in this study adopted religious beliefs in which a higher power or a deity was trusted for intervention and restoration of their health, similar to findings by (Kwah and Abdullahi, 2018). Literature shows that PWSCI who engage in religious practices adjust well to functional limitations and have renewed hope and psychological health with reduced risk of depression (Ghannad, Fateminik and Allipour, 2018; Muteti, Mlambo, Chikwasha and Chigonda, 2022). Religious practices may be an important tool for PWSCI to maintain psychological well-being and achieve good QoL.

Rehabilitation professionals should understand that religious beliefs form a major part of the coping strategies among PWSCI (Kwah and Abdullahi, 2018). Therefore, physiotherapists and other health professionals should incorporate programs that reinforce the religious coping strategies in the rehabilitation program to facilitate good quality of life among PWSCI. Furthermore, acceptance of the condition is interdependent with the religious coping strategy among PWSCI as reported by Kwah and Abdullahi (2018). Therefore, reinforcing the religious coping strategy can enhance

acceptance of the condition and the associated functional changes, and this can be key to promoting good quality of life among PWSCI.

5.4.3 Becoming self-reliant

This study also found that becoming self-reliant, a form of independence, was one of the coping strategies of PWSCI. This concurred with literature that shows that PWSCI made efforts to become independent in areas such as self-care and mobility (Babamohamadi, Negarandeh and Dehghan-Nayeri, 2011). In this way, PWSCI can focus on areas of their life they can have control over and achieve autonomy, thereby reducing psychological stress and achieving high life satisfaction and QoL. The findings of the current study are crucial for improving rehabilitation of PWSCI before discharge. To facilitate self-reliance in PWSCI, rehabilitation professionals should set patient-centred goals and PWSCI should be involved during goal setting to meet their daily life needs in areas of transfers, bed mobility, wheelchair use, self-catheterisation and pain management (Maribo, Jensen, Madsen and Handberg, 2020; Ørtenblad et al., 2023).

Furthermore, rehabilitation professionals can promote self-reliance in PWSCI by facilitating skill acquisition and mastery before discharge in areas of wheelchair mobility, use of adaptive equipment, transfers, pain management and prevention of other secondary health conditions (Glinsky and Harvey, 2024). The promotion of self-reliance among PWSCI may also involve fostering a problem-solving behaviour among PWSCI before discharge. For example, PWSCI can be trained to take initiative to repair damaged wheelchairs and inflate wheels of wheelchairs, among others. Lastly, to achieve self-reliance in PWSCI, rehabilitation professionals may also need to involve the PWSCI in structured community reintegration programs (Barclay, Robins, Migliorini and Lalor, 2021). Practising the use of public transport to get home and other outside environment activities before discharge (Barclay, Lalor, Migliorini and Robins, 2020). By exposing PWSCI to these community reintegration programs, they are able to learn to be independent in most important areas of their lives, and can easily reintegrate into the community successfully (Sulaiman et al., 2023)

5.4.4 Managing life with available resources

The current study findings indicate that PWSCI can manage life using available resources, demonstrating their resilience in their quest to survive and live a normal community life. Participants in the current study indicated the use of friends, family members and social environmental resources to meet their needs post-discharge. The PWSCI counted on family and friends as their means to connect with the real world, a demonstration of resilience, concurring with literature (Livneh and

Martz, 2014; Arya et al., 2016; Conti et al., 2020). The desire to get things done using the available resources demonstrates resourcefulness of PWSCI and is an important coping strategy for mitigating the challenges they experience. Participants in the current study also spent their time with family and friends as a coping strategy to mitigate stress and this is similar to literature (Budd, Gater and Channell, 2022).

Even though using this coping strategy demonstrates resourcefulness and resilience, it reveals serious shortcomings in rehabilitation clinical practice. Ideally, rehabilitation professionals should plan the discharge of PWSCI to ensure that PWSCI have post-discharge social support (Rezaei, Sharifi, Vaccaro and Rahimi-Movaghar, 2019). The plan involves making the accessibility to quality rehabilitation services and adequate community-based resources possible after discharge (Rezaei, Sharifi, Vaccaro and Rahimi-Movaghar, 2019). The fact that PWSCI depended heavily on family and friends to manage life highlights the need for rehabilitation professionals to facilitate peer support groups to be available for PWSCI to help them adapt to life with inadequate resources. Furthermore, rehabilitation should promote community-based rehabilitation to enhance follow-up care, mobilisation of community-based resources and home environment assessment

However, rehabilitation professionals struggle to make realistic and comprehensive discharge plans due to lack of human resources and funding, especially in low and middle-income countries like Malawi (Rezaei, Sharifi, Vaccaro and Rahimi-Movaghar, 2019). Therefore, there is a need for the ministry of health of Malawi to support rehabilitation programs aimed at improving the life of PWSCI with funding and human resources to improve the community reintegration of PWSCI.

5.5 Suggestions of people with spinal cord injury to improve their community reintegration

This study also explored the suggestions of PWSCI to facilitate their community reintegration, and two key suggestions emerged, namely, community members should be proactive in making environmental modifications and PWSCI should be adequately prepared for life after hospital discharge. These findings highlight the importance of a well-planned rehabilitation program to meet the needs of PWSCI.

5.5.1 Community proactiveness in environmental modifications

Environmental modifications may involve several activities such as the installation of ramps, bathrooms, and elevators, and making modifications to public transportation to improve accessibility of public facilities by PWSCI (de Serres-Lafontaine et al., 2023). Given the struggle of PWSCI to access architectural facilities and public transportation, a challenge that significantly reduces their

participation in community activities (Mohan and Deb, 2024), it is important to make these modifications to improve participation in community activities, good QoL and successful community reintegration. Social environmental modification is also crucial for creating a healthy, supportive and more inclusive social environment and can foster a sense of belonging for PWSCI (Mohan and Deb, 2024).

Furthermore, by teaming up with authorities, community members can also help create an accessible environment for every individual, including PWSCI by enforcing policies aimed at making public places, buildings and transportation universally accessible (Tsai et al., 2017). Rehabilitation team, especially physiotherapists, occupational therapists and social workers, can facilitate the community engagement by providing education to community members and providing guidance on the best ways of making the environment disability-friendly (Hertig-Godeschalk et al., 2018). Community engagement creates an inclusive environment where PWSCI do not feel isolated and can participate in various activities in any place of their choice.

In the context of Malawi, environmental modification can be a challenging venture considering several factors. Like in other low and middle-income countries, Malawi faces problems of lack of resources, financial problems, poor infrastructural planning, lack of transportation, stigma, cultural perceptions, lack of education on accessibility, lack of disability advocacy, weak governance and enforcement of disability laws, poor policies and many other problems (de Serres-Lafontaine et al., 2023; Nizeyimana, Louw, Phillips and Joseph, 2024). The interplay of these challenges can make it difficult for stakeholders to make meaningful modifications aimed at promoting community reintegration of PWSCI. However, a collective effort must be made to make these changes a reality.

5.5.2 Effective preparedness of PWSCI for home

Regarding the suggestion of adequately preparing PWSCI for life after hospital discharge, it is important to consider several factors. Literature shows that community-dwelling PWSCI often face many challenges in areas of self-care, mobility, employment, sexual health, depression, suicidal ideation, and social participation (Goetz et al., 2018; Halvorsen et al., 2021; Budd, Gater and Channell, 2022; Zizzo, Gater, Hough and Ibrahim, 2022). Inadequate preparation for life outside the hospital can be the beginning of experiencing numerous problems with the potential of worsening their health status in many areas of their life.

The findings of this current study highlight the need for the rehabilitation team to adequately prepare

the PWSCI for them to achieve good quality of life and community reintegration. Physiotherapists and occupational therapists can prepare the PWSCI by training them in areas of respiratory management, wheelchair mobility, activities of daily living, secondary health condition management, mental health support and facilitating coping strategies and resilience (Du Plessis et al., 2018; Glinsky and Harvey, 2024). Furthermore, the rehabilitation team can be instrumental in conducting home environment and community assessment to identify potential barriers and facilitators of the community reintegration of PWSCI, and make appropriate recommendations for modifications in the home environment such as widened doors, erecting ramps and grab bars, adjustable kitchen cabinets, lower showers for wheelchairs and other modifications to improve accessibility (Hertig-Godeschalk et al., 2018). Other important areas that rehabilitation team should consider during the preparation of PWSCI before discharge include vocational training, facilitating peer support group involvement and training use of public transportation which have positive impact on PWSCI (Sweet, Luc, Jean and and Martin Ginis, 2016; Rezaei, Sharifi, Vaccaro and Rahimi-Movaghar, 2019). Comprehensive preparation of PWSCI is multifaceted, and if done properly, it can significantly improve the functional, QoL, social participation and community reintegration outcomes for PWSCI. A collective effort needs to be adopted to realize this dream.

5.6 Conclusion

This chapter has discussed the challenges that PWSCI in this study experienced. It has also discussed the various coping strategies that they used to manage their life as they reintegrated into their communities. Lastly, the suggestions of PWSCI on how to further their community reintegration were also discussed in this chapter, highlighting the need for actions to be taken to promote their community reintegration.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

This study explored challenges that PWSCI face after hospital discharge including significant functional, health, vocational, and environmental challenges and lack of resources, all of which highlight the struggle of PWSCI in adjusting to community life after hospital discharge. These challenges pose serious barriers to the successful community reintegration of PWSCI in Malawian communities.

Even though they face these challenges, PWSCI adopted several coping strategies to adjust to a new, challenging life in the community and these included the use of spirituality and religious health practices, having an effective social support network, self-reliance, and managing resources, and these highlight the need for stakeholders to actively provide an effective support system to ensure successful community.

The study findings of key suggestions by PWSCI to further their community reintegration included the suggestion that the government should be proactive in environmental modifications and that PWSCI should be effectively prepared for community life after discharge, highlighting the need for a collective effort to enhance their community reintegration. To achieve this, health professionals should provide an effective, comprehensive, and realistic discharge plan aimed at addressing the issues likely to pose challenges for PWSCI after hospital discharge and how to capitalize on the facilitators. Community members should also be engaged early during rehabilitation so that they are educated on the importance of taking part in environmental modifications in readiness for the discharge of PWSCI. Community members can also form part of the support network. These can facilitate the adjustment to life at home for PWSCI and improve their community reintegration.

6.2 Strengths and weaknesses of the study

This study interviewed the PWSCI in their homes, allowing the researcher to understand the context in which PWSCI experienced their challenges. It also allowed the participants to express themselves comfortably in responding to the interview questions. The study was able to obtain rich information and all its objectives were achieved. Unfortunately, due to the purposive sampling from only one

rehabilitation centre, all the PWSCI who consented to participate in this study had TSCI. Those with NTSCI may have different experiences, as NTSCI tends to result in incomplete SCI than complete SCI. Furthermore, this study population was delimited to one rehabilitation centre, and therefore we cannot generalize these results not only to the wider population within the African context or globally.

6.3 Recommendations

The researcher recommends that future studies should explore the extent and impact of the challenges that people with spinal cord injury (PWSCI) face in the community. It is also recommended that future interventional studies be done to evaluate the effectiveness of environmental modifications and peer support groups. Furthermore, future research should look into the influence of the coping strategies of people with spinal cord injury on community reintegration. Future studies should also explore the impact of incorporating vocational rehabilitation on the community reintegration of people with spinal cord injury.

The findings of the current study also underscore the importance of comprehensive rehabilitation practices to enhance community reintegration of PWSCI. It is recommended that physiotherapists equip PWSCI with skills to manage pain, to identify, prevent and manage pressure sores and other secondary health conditions. Physiotherapists, occupational therapists and social workers should collaborate in training the PWSCI in community reintegration programs as part of the discharge plan. Rehabilitation should also ensure that sex therapists are accessible during inpatient rehabilitation to prepare the PWSCI for sexual life after discharge. Furthermore, it is recommended that rehabilitation should incorporate vocational rehabilitation programs in pre-discharge programs to prepare PWSCI for life in the community.

6.4 Reflexivity

The researcher used a phenomenological approach which showed the researcher the context-specific experiences and that every story the participants told was unique, despite the common threads that weaved the themes. Through this experience, the researcher learned the importance of incorporating programs in rehabilitation aimed at addressing issues that may affect PWSCI after discharge from the hospital. Furthermore, seeing the emphasis on the struggle of PWSCI in living their life in their homes, the researcher learned that clinical management is not a simple task but a complex process needing a coordinated effort of different stakeholders to ease PWSCI back into their homes and community for successful reintegration.

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APPENDICES

Appendix A: Information sheet

Title: Life experiences and perceived community reintegration of people with spinal cord injury after hospital discharge in Malawi

Dear Patient,

I, Aaron Mwafulirwa, a student at the University of the Witwatersrand in South Africa, am doing research on spinal cord injury, especially the experiences and perceived community reintegration of people who have this condition after being discharged from the hospital. I will provide you with information and then invite you to take part in this research. You may not decide today whether to take part in this study. Therefore, feel free to talk to anyone about this research. As we go through this information, there may be words that you do not understand. Therefore, you can stop me so that I explain, and if you have questions, you can ask them.

What is the purpose of this research?

Spinal cord injury results in life changes that bring about a lot of challenges. It is for this reason that I believe that you will help me to find out several things in this study. These things include your experience of life after being discharged from the hospital, your understanding of returning to the community after your injury, and the challenges you face in the wake of the injury to your back. Furthermore, I believe you will help me obtain suggestions to minimize the challenges you are facing because of your injury. **What type of research is this?**

In this research, you will take part by answering questions in an interview which will take about half an hour to 45 minutes.

Who is eligible to participate in this study?

You are eligible to participate in this study if you are at least 18 years of age or older and you have an injury to your back. You should be staying in Blantyre at the time of the research. I feel that your experience of life after injury will help me understand the experience of life after injury to your back.

Is participation in this study voluntary?

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

What is involved in this study?

If you accept to participate in the research, you will be given a consent form to sign. Afterward, you will be interviewed face-to-face by the researcher. During the interview, questions relating to your

experience of life after injury to your back will be asked, especially after being discharged from the hospital. Other questions will be related to how you are living within your home and the community at large. Lastly, the researcher will ask you questions that will be aimed at obtaining suggestions on how to minimize the challenges you face after your injury. The interviews will be audio-recorded, and you are asked to give consent to it.

Duration of the study

The research will take place for a period of three months, beginning in September 2022 and ending in November 2022. During this time, I will visit your home and community to conduct one interview with you which will last about 45 minutes.

Are there any risks to taking part in this study?

You will not be exposed to any risks in this study. However, some discomforts which include fatigue, boredom, mild emotional discomfort, and shyness may happen. Some of the questions may likely cause some emotional discomfort due to the sensitivity of the issues being discussed. Should any discomforts arise, please notify the researcher to seek the required help. You may also decide not to answer any questions on issues you feel uncomfortable to talk about.

What are the benefits of taking part in this study?

The possible benefits are that your participation will enable us to generate interventions aimed at minimizing the challenges that you face because of injury to your back.

Are there reimbursements for taking part in this study?

You will not be provided with any incentives for participating in the study and you will not spend any money for participating in this research.

Will the information be handled as confidential?

Your information obtained by the researcher will not be shared with any one person other than the researcher. However, we do not guarantee absolute confidentiality as personal information may be disclosed as required by law. To ensure confidentiality is maintained, all the names and identifiers on the files from the interviews will be replaced by codes to achieve anonymity. The research data will be kept in a locked cabinet in a secure room at Kamuzu University of Health Sciences and will only be accessed by the researcher.

Sharing the Results

Everything you tell me will not be shared with anyone else except my supervisor and nothing will be identified by your name. The results will be shared with the University of Witwatersrand as a requirement for my education. The results of this research will be shared with you. Later, it will be

made public through publications and other meetings.

Right to Refuse or Withdraw

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

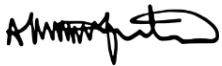
Who to Contact

For further information, please contact me at +265997136261 or send me an email at amwafulirwa@kuhes.ac.mw

This proposal has been reviewed and approved by the Human Research Ethics Committee of Kamuzu University of Health Sciences, which is a committee whose task is to make sure that research participants are protected from harm. If you wish to find out more about the Committee, please contact the COMREC Chairperson at

+265888118993 or send an email to comrec@medcol.mw

Kind regards



Aaron Mwafulirwa

Department of Physiotherapy

University of the Witwatersrand

Appendix B :Chikalata cha chidziwitso kwa otenga mbali pa kafukufuku

Mutu: Life experiences and perceived community reintegration of people with spinal cord injury after hospital discharge in Malawi

Okondendwa wotenga mbali,

Ine, Aaron Mwafulirwa, wophunzira pa sukulu ya ukachenjede ya Witwatersrand ku South Africa, ndikupanga kafukufuku wokhuza mene moyo wa anthu othyoka msana ukuyendera komanso momwe akukhalira kwawo akatulutsidwa ku chipatala. Ndikufotokozerani bwinobwino za kafukufukuyi ndipo pamapeto pake ndikupemphani kuti mutengepo gawo pa kafukufukuyi. Simuli wokakamizidwa kupanga chiganizo chotenga gawo pa kafukufukuyi lero ndipo muli ndi ufulu wofunsa anthu ena kuti mumvetse bwino musanapereke chilorezo cholowa mu kafukufukuyi. Pamene ndikufotokoza zokhuza kafukufukuyi, pali zinthu zina zomwe nkutheka simungazimvetse. Choncho, khalani womasuka kundiimitsa kuti ndifotokoze momveka bwino ngati muli ndi mafunso.

Cholinga cha kafukufukuyi ndi chiyani?

Kuthyoka msana kumabweretsa kusintha kwakukulu pa moyo wa munthu ndipo kumabweretsa zovuta zambiri. Choncho, ndikukhulupilira kuti mundithandiza kuti ndidziwe zinthu zingapo mu kafukufukuyi. Zinthuzi ndi monga mene moyo wanu ukuyendera pamene mwatulutsidwa ku chipatala komanso zovuta zomwe mukukumana nazo pamboyo pa kuvulaka kwa msana wanu. Kuonjezera apo, ndikukhulupilira kuti mundithandiza kupeza maganizo anu okhuza momwe tingachepetsere zovuta zomwe mukukumana nazo chivulalireni msana wanu.

Kodi ndi mtundu wanji wa kafukufuku?

Mu kafukufuyi, mukhala macheza omwe tidzakufunsani mafunso osiyanasiyana ndipo machezawa adzatenga mphindi zokwana 45.

Kodi oyenera kutengapo gawo mu kafukufukuyi ndi ndani?

Ndinu wololedwa kutenga nawo gawo mukafukufukuyi ngati muli ndi zaka 18 kapena kupitilira apo ndipo muli ndi vuto lothyola msana. Mukuyenera kuti mumakhala m'boma la Blantyre pa nthawi ya kafukufukuyi. Ndili ndi chikhulupiliro kuti mundithandizira kumvetsetsa mene moyo wanu ukuyendera chithyokere msana wanu.

Kodi kutenga nawo gawo pa kafukufukuyi ndi kokakamizidwa?

Kutenga mbali pa kafukufukuyu ndi kosakakamizidwa ndipo kukana kutenga nawo mbali sikuchititsa kuti mulandire chilango kapena kutayika kwa zabwino zomwe muli ndi ufulu wolandira pamoyo wanu. Muthanso kusiya kutenga gawo pa kafukufukuyu nthawi iliyonse popanda kulandira chilango chilichonse.

Kodi zochitika mu kafukufukuyu ndi chani?

Ngati muvomereze kutenga gawo pa kafukufukuyi, mudzapatsidwa fomu yovomereza kulowa mu kafukufukuyu kuti musayinire. Kenako tidzayamba macheza athu ndipo panthawiyi mudzafunsidwa mafunso okhuza mene moyo wanu ukuyendera pambuyo pa kuthyoka kwa msana wanu. Ena mwa mafunso omwe mudzafunsidwe adzakhala ofuna kudziwa momwe mukukhalira pakhomu panu komanso mdera lanu lonse. Pomaliza, mudzafunsidwa kuti mupereke maganizo anu pa nkhani yofuna kuchepetsa mavuto omwe mumakumana nawo Kamba kothyoka msana wanu. Zokambirana pa nthawi ya macheza athu zidzajambulidwa ndipo mukufunsidwa kupereka chilorezo kuti izi zichitike.

Nthawi yomwe kafukufuku adzachitike

Kafukufukuyi achitika kwa miyezi itatu, kuchokera mwezi wa Seputembala mpaka Novembala mu chaka cha 2022. Munthawiyi, ine ndidzabwera komwemumakhala ndipo tidzachita macheza athu omwe adzatenge pafupifupi mphindi 45.

Kodi pali zoopsa kapena zovuta zomwe mungakumane nazo potenga nawo mbali pa kafukufukuyi?

Simudzapezeka pachiwopsezo chilichonse nmukafukufukuyi. Komabe, zovuta zina zomwe zitha kukhala kutopa, kunyong'onyeka, kusakhazikika pamtima pang'ono komanso manyazi ndipo zovutazi zidzachepetsedwa mu kafukufukuyu. Ndi zothekanso kuti mafunso ena atha kukusokonezani maganizo anu chifukwa ndi ovuta kuyankha. Ngati pangakhale zovuta zina, chonde dziwitsani mwini wa kafukufuku kuti muthandizidwe moyenera.

Phindu lotenga nawo gawo pa kafukufuku

Phindu lomwe lilipo potenga nawo gawo mukafukufukuyi ndi loti mutithandiza kupeza njira zomwe tingagwiritse ntchito pochepetsa mavuto omwe mumakumana nawo kamba kothyoka msana.

Kodi mudzapatsidwa mphoto kapena ndalama chifukwa chotenga gawo pa kafukufukuyi?

Simudzapatsidwa mphoto iliyonse kapena ndalama kamba kotenga gawo pa kafukufukuyi ndipo

simudzaononga ndalama chifukwa chotenga gawo pa kafukufukuyi.

Kusunga chinsisi

Zokambirana zonse zomwe zidzachitike sidzidzaperekedwa kwa anthu ena omwe sakupanga nawo kafukufukuyi. Komabe, sitikutsimikizira zachinsinsi kwathunthu chifukwa zinthu zina zitha kuululidwa ku bwalo la milandu monga mwa malamulo a dziko lino. Poonetsetsa kuti chinsisi chasungidwa, maina onse komanso chilichonse chomwe chingapangitse kuti mudziwike chidzachotsedwa ndipo tidzaika mawu a chinsisi mmalo mwake. Zotsatira zonse za kafukufuku zidasungidwa mchipinda chokhoma ku sukulu ya za umoyo ya Kamuzu University of Health Sciences.

Kugawa kwa zotsatira za kafukufukuyi

Zinthu zonse zomwe mutiuze mukafukufukuyi sidzidzaperekedwa kwa aliyense kupatula aphunzitsi anga ndipo palibe chomwe chidzakhale ndi dzina lanu. Zotsatirazi zidzatumizidwa ku sukulu ya University ya Witwatersrand ngati mbali imodzi yamaphunziro anga. Zotsatirazi zidzatumizidwanso kwa inu. Pamapeto pake, zidzagawidwa kuti anthu ena adziwe kudzera njira zoyenera zofalitsira uthenga monga intaneti komanso misonkhano.

Ufulu wokana komanso kutuluka mukafukufukuyi

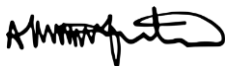
Kutenga mbali pa kafukufukuyu ndi kosakakamizidwa ndipo kukana kutenga nawo mbali sikuchititsa kuti mulandire chilango kapena kutayika kwa zabwino zomwe muli ndi ufulu wolandira pamoyo wanu. Muthanso kusiya kutenga gawo pa kafukufukuyu nthawi iliyonse popanda kulandira chilango chilichonse.

Oti mutha kuyankhula nawo

Kuti mudziwe zambiri, chonde ndiimbireni pa +265997136261 kapena kutumiza uthenga ku amwafulirwa@kuhes.ac.mw

Kafukufukuyi waunikiridwa komanso kuvomerezedwa ndi komiti yoteteza anthu otenga gawo pa kafukufuku ya Kamuzu University of Health Sciences. Ngati mukufuna kudziwa zambiri za komitiyi, chonde yankhulani ndi mkhala pampando wa komitiyi pa +265888118993 kapena tumizani uthenga ku comrec@medcol.mw.

Mafuno onse abwino,



Aaron Mwafulirwa

Department of Physiotherapy University of the Witwatersrand.

Appendix C: Participant consent form

Study title: Life experiences and perceived community reintegration of people with spinal cord injury after hospital discharge in Malawi

I have been invited to take part in this study about my life experiences after the injury to my back.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any question I have asked has been answered to my satisfaction. I consent voluntarily to be a participant in this study. I also voluntarily consent to the tape recording of the interviews.

Name of Participant _____

Signature of Participant _____

Date _____

Day/month/year

If the participant is illiterate ¹

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Name of witness
participant

Thumbprint of

Signature of witness _____



Date _____

Day/month/year

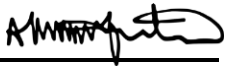
Statement by the researcher

I have accurately read out the information sheet to the potential participant and, to the best of my ability, made sure that the participant understands that the following will be done:

1. Interview up to 45 minutes
2. The interviews will be audio-recorded, and the participant should give consent to the same.

I confirm that the participant was allowed to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this Informed Consent Form has been provided to the participant.

Name of Researcher _____ Signature of Researcher  _____

Date _____

Day/month/year

Appendix D: Fomu ya chilolezo chotenga mbali pa kafukufuku

Fomu ya chilorezo

Mutu: Life experiences and perceived community reintegration of people with spinal cord injury after hospital discharge in Malawi

Ndapemphedwa kuti nditenge gawo pa kafukufuku wokhuza mene moyo wanga ukuyendera pambuyo pa kuthyoka kwa msana wanga.

Ndawerenga bwinobwino chikalata chokhuza kafukufukuyi , kapena andiwerengera . Ndinali ndi mwayi wofunsa mafunso okhuza kafukufukuyi ndi mafunso onse ayankhidwa bwino ndipo ndakhutira. Ndikuvomera mosakakamizidwa kutenga gawo pa kafukufukuyi.

Dzina la wotenga gawo pa kafukufuku _____ Sayini ya wotenga gawo pa kafukufuku _____ Tsiku ____
Tsiku/mwezi/chaka

Ngati wotenga gawo pa kafukufuku sadziwa kuwerenga komanso kulemba

Ndachitira umboni kuwerengeredwa momveka bwino kwa form ya chilorezo kwa yemwe wapemphedwa kuti atenge gawo pa kafukufuku, ndipo munthuyi anapatsidwa mwayi wofunsa mafunso. Ndikutsimikiza kuti munthuyu wamovereza kutenga gawo pa kafukufukuyi mosakakamizidwa.

Dzina la mboni _____
mboni _____
Tsiku _____
Tsiku/mwezi/chaka

Chidindo cha chala cha wotenga mbali Sayini ya



Mawu a Mwini Kafukufuku

Ndawerenga momveka bwino chikalata cholongosola zambiri za kafukufukuyi kwa yemwe ndamupempha kuti atenge gawo pa kafukufukuyi ndipo ndayesesa kuti amvetsetse kuti zotsatirazi zichitika mukafukufukuyi:

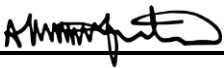
1. Macheza ofunsana mafunso atenga mphindi pafupifupi 45

2. Zokambirana pa machezawa zidzajambulidwa ndi chojambulira mawu ndipo wotenga mbali pa kafukufuku akuyenera kupereka chilorezo kuti izi zichitike.

Ndikutsimikiza kuti wotenga gawo pa kafukufuku anapatsidwa mwayi kuti afunse mafunso okhuza kafukufukuyi, ndipo mafunso onse omwe anafunsa ayankhidwa moyenera molingana ndi kuthekera kwanga. Ndikutsimikizanso kuti munthuyu sanaumirizidwe kuti avomereze kutenga gawo pa kafukufukuyi, ndipo chilorezo chaperekedwa mwaufulu komanso mosakakamizidwa.

Ndaperekanso fomu ya chilorezoyi kwa wotenga gawo pa kafukufukuyi.

Dzina la Mwini wa kafukufuku _____

Sayini ya Mwini wa kafukufuku _____ 

Tsiku _____

Tsiku /mwezi/chaka

Appendix E: Interview Schedule

Category	Open-ended questions	Probing questions
Personal	1. Tell me about your experience of leaving the spinal unit/ hospital to your home and the community.	- How prepared were you for leaving the spinal unit? - What were the things you felt good about leaving hospital? - What did you find hard about leaving hospital?
	2. Now that you're out of hospital, how has your life changed since the SCI?	-what did you do before the SCI that you no longer do now (including leisure activities) - How does the difference in doing things now make you feel? - Are you happy? - What makes you happy? - Are you satisfied with your life circumstances? -is there anything that makes your life circumstances easy or hard?
	3. What are the positive aspects that came up once you	-Where these positive aspects self-created or created by those around you?

	became settled at home after discharge, if any?	
	4. What are the challenges that came up once you became settled at home after discharge, if any?	-What are your coping strategies to mitigate the challenges you face at home?
	5. What do you think can be done to minimize the challenges you face at home and in the community?	-What can be done by yourself? -What can be done by your family or community?
Environment	6. Can you tell me about the people or the things that have helped you to return home and settle back into the community after SCI?	- Did people help you? - What did they do? - How did it make you feel? How long did they help you for?
	7. Can you tell me about the things that made it difficult to return home and get back to normal living and things which have prevented you from being able to settle back into the community?	- What was difficult? - Why was it difficult? - How did it make you feel? -Did you overcome difficulty? If yes, how?
	8. Can you tell me about the support you have received when returning into	- Did the support help you? - Is there anyone who didn't give you support? How do you feel about it?

	the community and where you received it from?	
Occupation	9. Please explain to me how you get around your house and the community and if there are any difficulties?	- How do you get to different rooms in house, to the garden, to the shops, to the clinic etc.? - Is it difficult/ easy? - What makes it easy/difficult? - How has it changed? -How do you feel about the changes?
	10. Please explain your experience of work before and after SCI	- Is it difficult to complete tasks that are part of your job requirement? -How do you feel about your work environment and circumstances - How do you get to work? -What are your working hours?
Closing	11. What advice would you like to add for someone who is about to be discharged home?	What can be done by the health professionals to prepare a person with SCI for home?

Appendix F: Fomu ya mafunso

GURU LA MAFUNSO	MAFUNSO OTSEGUKA	MAFUNSO OWONJEZERA
ZOKHUZA MOYO WANU	1. Ndiuzeni kuti munamva bwanji m'moyo mwanu pamene mumachoka ku chipatala kupita kunyumba kwanu komanso kudera lanu	-Munali okonzeka motoni zokhuzakutulutsidwa kuchipatala? -Ndi zinthu ziti zomwe munamva bwino pochoka kuchipatala? -N'chiyani comwe chimakudandaulitsani pamene mumachoka kuchipatala? -Nchiyani chimakusangalatsani ? -Kodi ndinu okhutitsidwa ndi moyo wanu? -Kodi pali chilichonse chomwe chimapangitsa moyo wanu kukhala wovuta kapena wosavuta?
	2. Tsopano popeza mwatuluka mchipatala, moyo wanu wasintha bwanji chivulalireni msana wanu?	-Kodi ndi zinthu ziti munkachita musanavulare msana zomwe

		mukukanika kuchitanso pano? -Nanga pano mukuwanitsa zinthu ziti? (izi zikuphatikiza zisangalalo) -Kodi kusiyana kwa kachitidwe ka zinthu kumeneku kumakupangitsani kumva bwanji? -Ndinu osangalala?
	3. Ndi zinthu zabwino ziti zomwe zidabwera mutakhazikika kunyumba mutatuluka kuchipatala, ngati zilipo?	-zinthu zabwinozi mumadzipangira nokha kapena kupangiridwa ndi omwe akuzungulirani?
	4. Ndi zovuta zANJI zomwe zidabwera mutakhazikika kunyumba mutatuluka, ngati zilipo?	-Ndi njira ziti zothanirana ndi mavuto omwe mumakumana nawo kunyumba ngati zilipo?
	5. Mukuganiza kuti chingachitike ndi chiyani kuti muchepetse zovuta zomwe mumakumana nazo kunyumba ndi mdera lanu?	-Ndi chiyani chomwe mungachite panokha? -Ndi chiyani chomwe

		chingachitidwe ndi banja lanu kapena dera lanu?
ZOKHUZA KOMWE MUKUKHALA	6. kodi mungandiuze za anthu kapena zinthu zomwe zakuthandizani kuti mubwere kunyumba ndikukhazikikanso mdera lanu pambuyo povulala?	-Kodi anthu anakuthandizani? - Anachita chiyani? -Zinakupangitsani kumva bwanji? - Adakuthandizani nthawi yayitali bwanji?
	7. Kodi mungandiuze zinthu zomwe zidapangitsa kuti zikhale zovuta kubwelera kunyumba ndi kuyambiransi moyo wabwino komanso zinthu zomwe zidakulepheletsani kukhazikika m'dera lanu?	- Chinali chovuta ndi chiyani? - Chifukwa chiyani zinali zovuta? -Zinakupangitsani kumva bwanji? -Kodi munagonjetsa zovuta zanu? Ngati inde, zinatheka bwanji?
	8. Kodi mungandiuze chithandizo chomwe munalandira pobwerera kumudzi komanso komwe mudachilandira?	-Kodi chithandizochi chinakuthandizani? -Kodi alipo amene sanakuthandizeni? -kodi munamva bwanji?
ZOKHUZA NTCHITO	9. Mungandifotokozere momwe mumayendera kunyumba kwanu komanso dera lanu komanso ngati pali zovuta?	-Mumafika bwanji ku zipinda zosiyanasiyana mnyumba mwanu, m'dimba, m'masitolo, kuchipatala ndi zina zambiri? -Ndizovuta / zosavuta? -Nchiyani chimapangitsa kukhala zosavuta / zovuta? -Kodi zasintha bwanji?

		-Kodi mukumva bwanji ndi kusinthaku?
	10. Chonde fotokozani zomwe mwakumana nazo pantchito musanavulare komanso pambuyo povulala msana wanu?	- Kodi ndizovuta kumaliza ntchito zomwe zili gawo la ntchito yanu? -Kodi mumamva bwanji mukamagwira ntchito komanso mmene zinthu zilili kutchito kwanu? - Kodi mumapita bwanji kuntchito? - Mumagwira ntchito nthawi yaitali bwanji?
	11. Ndi malangizo ati omwe mungafune kupereka kwa munthu amene watsala pang'ono kutulutsidwa kuchipatala	Kodi angachite chiyani akatswiri a zaumoyo kuti akonzekeretse munthu wovulala msana kuti apite kunyumba?

Appendix G: Demographic data form

Descriptor			
Age			
Gender			
Years living with SCI			
General LOS in months during in patient rehab			
If they are continuing with any out-patient rehab			
Type of occupation before SCI			
Type of occupation after SCI			
Marital status before SCI			
Marital status after SCI			
Neurological level of injury / Diagnosis			
Completeness of injury			
Cause of injury			
Level of education			

Appendix H: Queen Elizabeth Central Hospital Permission Letters

Telephone: (265)674 333/677 333
Facsimile: (265)674 603
Email: queenshospital@malawi.net

All Communications should be addressed to:
The Hospital Director



In reply please quote No.
QUEEN ELIZABETH CENTRAL HOSPITAL
MINISTRY OF HEALTH
P. O. BOX 95
BLANTYRE
MALAWI

22/11/2020

TO WHOM IT MAY CONCERN

Dear Sir,

RE: PERMISSION TO CONDUCT RESEARCH IN THE ORTHOPAEDIC DEPARTMENT

I have reviewed your request to conduct a research project on *life experiences and perceived community re-integration of people with spinal cord injury after hospital discharge at Queen Elizabeth Central Hospital* in fulfilment for your masters studies at the university of Witwatersrand. I feel this research will be beneficial to inform management of patients with spinal cord injuries and help easier community re-integration in future. I am therefore pleased to inform that I give permission in respect to your research request and access to the patient files from the adult orthopaedic wards. Your initiative is appreciable and am ready to support this research at my best.

Please be mindful and practise your ethical considerations, respect patient privacy and confidentiality. I would expect professional conduct throughout the clinical areas.

I wish you all the best in your research.

Yours faithfully



Dr Nohakhelha Nyamulani, MBBS (MW) MSc (Edinburg) FCS ECSA (ORTHO)
Orthopaedic and Trauma Specialist Surgeon
Head of Orthopaedic and Trauma Surgery Department-QECH

Telephone: (265) 01 874 333 /877 333
Facsimile: (265) 01 876928
Email: queenshosp@globemw.net

All communications should be addressed to: **The Hospital Director**



In reply please quote **No. QECH/ADMN/**

QUEEN ELIZABETH CENTRAL HOSPITAL
P.O. BOX 95
BLANTYRE
MALAWI

23 November, 2020

Dear Sir,

SUPPORT LETTER FOR AARON MWAFULIRWA

REF: Life experiences and perceived community re-integration of people with spinal cord injury after hospital discharge in Malawi

I write in support of the above mentioned study. I have read through the proposal, the investigator needs access to the records of patients from the physiotherapy department, which is possible to get.

I understand the study will be focusing on life experience of people with Spinal Cord injury after discharge from the hospital. The study will provide information on what happens to patients with spinal cord injury after discharge from hospital, the challenges they face and how the community perceives them.

I hope the study results will be shared with the department and presented to the hospital research team.

Sincerely,

A handwritten signature in black ink, appearing to be 'T. Mankhokwe'.

Talumba Mankhokwe (Principal Physiotherapist)
HEAD OF PHYSIOTHERAPY DEPARTMENT
Tel: +265882878406,
E-mail: tmankhokwe1@gmail.com

Appendix I: Kachere Rehabilitation Centre Permission Letter



MAP

MALAWI AGAINST PHYSICAL DISABILITIES

16th December 2020

Mr. Aaron Mwafurirwa,
COM.,
Physiotherapy Dept.,
Blantyre.

Dear Sir,

**REQUEST FOR PERMISSION TO CONDUCT RESEARCH AT KACHERE
REHABILITATION CENTRE.**

The above captioned matter refers. You are permitted to come to the Centre and conduct your piece of research on your selected topic. When you are ready, contact Mr. Bester Kamakanda or Mr. Foster Robin to help you with what you need for your work.

Please remember to share with us the results and recommendations of the research to see if we can consider implementing that which can help the Centre.

I wish you well on your studies.

MAK Dzinkambani
General Manager

cc. Mr. Kamakanda
Mr. Robin



IN WAGING WAR ON DISABILITIES IN MALAWI!
WE NEED YOUR SUPPORT

P.O. BOX 256, BLANTYRE, MALAWI. PHONE: 01 877951, 0999935757, 0888432757 FAX: 01 811 604

Appendix J: Medical Council of Malawi Registration Certificate



CERTIFICATE OF REGISTRATION

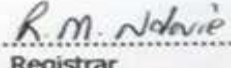
REGISTRATION NO. MCM/PHY/0272 CERTIFICATE NO:372

This is to certify that
AARON YAULUNGU MWAFULIRWA

is this 23rd day of August 2019, registered on the
Register of **PHYSIOTHERAPISTS**
kept by the Medical Council of Malawi in accordance with the
provisions of the Medical Practitioners and Dentists Act, 1987,
and the Regulations made thereunder.




Chairman

 
Registrar

Appendix K: COMREC application fee

 **Standard Bank**
Cash Deposit Receipt

Date: 2022/07/20 Time: 12:40:39

Deposit Amount
MWK 195,000.00

Account Name
M/S COLLEGE OF MEDICINE

Account Number
9100003028906

Reference
AARON MWAFULIRWA 0997136261

Branch
GINNERY CORNER

Transaction ID
1033586

Standard Bank Malawi
This transaction has been
processed electronically
and needs no further
authentication

Customer Information
Every effort has been made to ensure the accuracy and completeness of the information contained in this transaction. Please review the details at your soonest convenience and in the unlikely event of any discrepancy please bring this to our attention. We would be happy to clarify any queries you might have.

Contact Us For any queries please call Customer Contact Centre 247 / +265885920001 / +2653999015001. Our lines are open Monday to Friday, 8:00 to 18:00. Alternatively please email us. E-mail: Customercare@standardbank.co.mw

Mal 13/905011A

Standard Bank. IT CAN BE™

Appendix L: Letter of Support from the Department of Rehabilitation Science (KUHES)



To: The Chairperson, College of Medicine Research Ethics Committee (COMREC)
From: Head, Rehabilitation Sciences
Date: 20th July 2022

Dear Sir,

SUPPORT FOR Mr. A. MWAFULIRWA'S PROTOCOL SUBMISSION TO COMREC

I write to support Mr. A Mwafulirwa's submission of his research protocol for review to COMREC. His research protocol is entitled, "**LIFE EXPERIENCES AND PERCEIVED COMMUNITY RE-INTEGRATION OF PEOPLE WITH SPINAL CORD INJURY AFTER HOSPITAL DISCHARGE IN MALAWI.**"

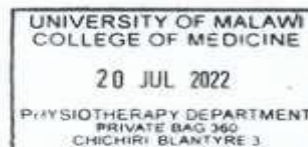
The department will render the required support to this study until its completion.

I look forward to your usual assistance in this matter.

Yours Faithfully,

A handwritten signature in black ink, appearing to read "Anderson Mughogho".

Anderson Mughogho



Appendix M: Principal Investigator's Curriculum Vitae

BIOGRAPHICAL SKETCH

Name: Aaron Mwafulirwa

Position title: Assistant Lecturer

Institution: Kamuzu University of Health Sciences

EDUCATION/TRAINING

Awarding Institution	Degree	Completion date	FIELD OF STUDY
University of Malawi, College of Medicine	BSc (honors)	06/2014	Physiotherapy
University of Malawi, College of Medicine	Certificate	2018	Mechanical Diagnosis and Therapy
University of Witwatersrand	MSc	Continuing	Neurology and neurosurgery for Physiotherapists

PERSONAL STATEMENT

With the growing burden of neurological conditions, I have the passion to improve life of individuals with neurological conditions such as spinal cord injury in Malawi and beyond. This will be achieved through high-impact research and teaching. Therefore, my objective is to become an excellent individual well-equipped with high-quality knowledge and skills in clinical Neurological Physiotherapy, general health, and research.

Currently, I am pursuing a master's degree in neurological physiotherapy at the University of Witwatersrand in South Africa. My study focuses on exploring the life experiences and community reintegration of people with spinal cord injury after hospital discharge. This study will set precedence for more high-quality studies on people with spinal cord injury aimed at improving their quality of life.

POSITIONS AND HONOURS

Positions and Employment

- 2015- Present. Assistant Lecturer, Kamuzu University of Health Sciences
- 2014 - 2015, Intern Physiotherapist, Queen Elizabeth Central Hospital

Professional Memberships

- Member Physiotherapy Association of Malawi.
- Registered member of the Medical Council of Malawi

Honors

- Awarded Best Science Student in form 4 the year of 2008 at Zomba Catholic Secondary School.

Other responsibilities and achievements

- **2016:** Participant in the physiotherapy curriculum review – Neurology modules
- **2022:** Current Physiotherapy year 4 class coordinator.

ONGOING RESEARCH

A qualitative study on life experiences and perceived community reintegration of people with spinal cord injury after hospital discharge in Malawi.

Appendix N: Supervisor's Curriculum Vitae

Kholofelo Mashola Curriculum Vitae

PERSONAL INFORMATION					
Surname	Mashola			First names	Mokgadi Kholofelo
Title	Miss	Gender	Female	ID Number	8806190305088
Citizenship	RSA			Population group	African
Place of birth	South Africa			Date of birth	19/06/1988
Tax number	0494700164			Direct number	0825247594
E-mails	kholofelo.mashola@wits.ac.za (work); kholofelo.mashola@up.ac.za (research)				
Reviewer for journals	Spinal Cord; South African Journal of Physiotherapy; African Journal of Disability				
Membership in national and international bodies					
Body			Position		
Southern African Spinal Cord Association			Vice Chairperson		
South African Society of Physiotherapy			General member		
			Special interest groups: Pain Management Physiotherapy Group Neurological Rehabilitation Physiotherapy Group		
			General member		
PainSA			General member		
International Spinal Cord Society			General member		
World Confederation for Physical Therapy			General member		
			Special interest group: International Network of Spinal cord injury Physiotherapists (SCI-PT)		

EDUCATION				
Degree	Field of study	Higher education institution	Year	Distinctions
PhD	Physiotherapy: Spinal cord injury	University of Pretoria	2018 - Present	n/a
MPhysT	Physiotherapy	University of Pretoria	2016	None
BSc (Physio)	Physiotherapy	University of Limpopo, Medunsa Campus	2009	Undergraduate Research (2009) English Language III (2008) Chemistry (2006)

WORK EXPERIENCE		
Name of employer	Capacity and/or type of work	Period From mm/yy to mm/yy
University of the Witwatersrand	Lecturer: Adult Neurology	01/10/2019 - Present
University of Pretoria	Lecturer: Spinal Cord Injury (Full-time)	01/10/2016 - 01/09/2019
University of Pretoria	Research Assistant (Part-time)	01/03/2016 - 30/09/2016
University of Pretoria	Lecturer: Spinal Cord Injury (Part-time)	01/01/2016 - 30/09/2016
University of Pretoria	Neurology Clinical Supervisor (Part-time)	01/01/2015 - 30/09/2016
Sefako Makgatho Health Science University	Neurology Clinical Supervisor (Part-time)	01/03/2014 - 30/09/2016
Phaswana & Mazibuko Partners	Physiotherapist (Full-time)	01/08/2014 - 31/12/2015
Rita Henn & Associates	Spinal Physiotherapist (Full-time)	01/08/2012 - 31/07/2014
SunPhysio & Associates	Physiotherapist (Full-time)	01/01/2012 - 31/05/2015
Polokwane Provincial Hospital	Physiotherapist (Full-time)	01/01/2010 - 31/12/2011

Awards and scientific/scholarly recognition	Role	Year
Best Research Presentation – Third prize	Supervisor	2020
Best Research Presentation – Third prize	Supervisor	2019
Outstanding contribution to research in the physiotherapy department	Employee	2018
Best Research Presentation (shared)	Supervisor	2018
Best Research Presentation	Supervisor	2017
Best Research Project; Best Research Presentation	Supervisor	2016
Best physiotherapy clinician at Polokwane Hospital, Limpopo.	Employee	2011
Certificate of appreciation in recognition of valuable contributions to the field of physiotherapy	Employee	2011
Best Research Project	Student	2009

Professional presentations

- Mashola, M.K. 2020. The experience of pain by people with spinal cord injury. Clinical Solutions Evening lecture CA September 2020
- Mashola, M.K., Korkie FE & Molhabeng, D.J. 2020. The risk of pain medication misuse in people with spinal cord injury. Poster presented at 59th ISCoS Annual Scientific Meeting, Virtual, "5 September 2020.
- Mashola, M.K., Mo'habeng, D.J. 2019. Associations between health behavior, secondary health conditions and quality of life in people with spinal cord injury. Poster presented at 1st DC:PT Congress at Palaxpo, Geneva, Switzerland, 10th - 12 May 2016.
- Du Plessis, M., McGaffin, C.R., Molepo, T., Oelofse, R., Van Zyl, S. & Mashola, M.K. 2018. Perceived readiness for hospital discharge: Patients with spinal cord injury versus physiotherapists. Podium presentation at the SA3CA/3AMRA congress at Riversands, Johannesburg, South Africa 23-25 August 20th B.
- Mashola, M.K., Mo'habeng, D.J. 2017. The influence of leisure time physical activity on secondary health conditions and quality of life in people with spinal cord injury. Poster presented at the 56th ISCoS Annual Scientific Meeting in Dublin, Ireland, 24-26 October 2017.
- Mashola, M.K., Mo'habeng, D.J. & Olorunju S. 2017. Readmission due to secondary health conditions in people with spinal cord injury at a private rehabilitation facility in South Africa. Poster presented at WCPT Congress at the ICC, Cape Town, South Africa, 2-4 July 2017.
- Swanepoel, A., Pieterse, A., Nhlapho, J.M., Brian, K., Vaganar, L., Lukhele, Z. & Mashola, H. 20th 7. Perceived job risk factors associated with work-related musculoskeletal disorders in nurses working in spinal cord injury rehabilitation units. Poster presented at WCPT Congress at the ICC, Cape Town, South Africa, 2-4 July 2017.
- Mashola, M.K., Mo'habeng, D.J. & Olorunju S. 2014. The influence of discharge outcome levels on readmission to hospital following spinal cord injury rehabilitation. Poster presented at the 1st Biennial 3ASCA Congress at C3IR Conforanra Cen'tro Potnria, South Africa 4-6 October 2014
- Mashola, M.K., Mo'habeng, D.J. & Olorunju S. 2014. Influence of discharge outcome levels on readmission to a hospital following spinal cord injury rehabilitation. Poster presented at the Health Sciences Faculty Research day, University of Pretoria, 19-20 August 2014 IFD/201442C1.
- 3kaal, L. & Mashola, M.K. 2010. The prevalence of stress incontinence and its impact on quality of life among the male staff at the University of Limpopo Medunsa Campus. Paper presented at Research Day, University of Limpopo (Medunsa campus), 1st August 2010.

Publications in peer-reviewed journals

- Mashola, M.K., Korkie E. & Mothabang, D.J. 2020. 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 1st 144152
- De Lange, J.S., Jacobs, J., Meiring, N., Hloroane, B., Varster, T., Olorunju, S. & Mashola, M.K. 2020. Reliability and validity of the Readiness for Hospital Discharge Scale in patients with spinal cord injury. South African Journal of Physiotherapy, 78(1), 40C.
- Mashola, H. & Molhabeng, D.J. 20th 9. Associations between health behaviour, secondary health conditions and quality of life in people with spinal cord injury. African Journal of Disability 8(1) 463
- Mashola, N. K., Olorunju, S. & Mothabang, D.J. 2019. Factors related to hospital readmissions in people with spinal cord injury in South Africa. South African Medical Journal, 109(2): 107-111.
- Du Plessis, M., McGaffin, C.R., Molepo, T., Oelofse, R., Van Zyl, S. & Mashola, H. 2016. Perceived readiness for hospital discharge: Patients with spinal cord injury versus physiotherapists. South African Journal of Physiotherapy, 74(1), 45-52.
- Brienen, B., Lukhele, Z., Nhlapho, J.M., Pieterse, A., Swanepoel, A., Vagener, L. & Mashola, M.K. 2018. Work-related musculoskeletal disorders in nurses working in South African spinal cord rehabilitation units. International Journal of Africa Nursing Sciences 1(1): 7-11
- 3kaal, L. & Mashola, H. 201st The prevalence of urinary incontinence and its impact on quality of life among the female staff at the University of Limpopo Medunsa campus. South African Journal of Physiotherapy, 67 (C): 45-52.

Relevant rehabilitation courses attended

Nama	Yaar
Certificate in Pain (3 of 6 Modules)	2020
The advanced course. Theory & Practice WCPT2018/003/0004	2019
Physiotherapy management of spinal cord injuries (WPT2014/04/001)	2014
Pharmaceutical research with WHO PBPO10.613/02/2013	2013
Neuro Rehabilitation. An outcome-based approach MCI within the ICF 0901067.*1	2012
Rehabilitation in Action (STA007/28/04/2011d)	2011
Spinal Cord Injury workshop 08/08/2011	2011
Interpretation of MRI's, IT scans and chest X-rays (PBO07/004.*07/201g)	2010

Name	Reference	Relationship
Prof Varonica Ntse	011 717 3721 "errata" is a	Current line manager, University of Limpopo

Appendix O: Ethics Approval from COMREC



Appendix P: Ethics approval from the University of Witwatersrand



Office of the Deputy Vice-Chancellor Research and Innovation

YO, J/ir A Mwefulirwe
School of Therapeutic Sciences
Department of Physiotherapy
Medical School
University

E-mail: 2061068@wits.ac.za

CC: Supervisor: Ms K Maerola
<Kholofe@wits.ac.za>
and <HREC@wits.ac.za>

FROM: Mr Iain Burns
Human Research Ethics Committee (Medical)
Tel: 011 7 7 1252
E-mail: Iain.Burns@wits.ac.za

DATE: 2023/04/04

REF: R 14/49

PROTOCOL NO: M201669 (This is your ethics application reference number. Please quote it in all enquiries, oral or written, relating to this study.)

PROJECT TITLE: *Life experiences and perspectives of community re-integration of people with spinal cord injury after hospital discharge*

Please find attached the Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on you and our institution and contribute to the enhancement of the University.

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F'149 Mr A tdwafuliwa

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M201009

NAME:
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DEPARTMENT:

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DATE CONSIDERED:

2020E10/30

DECISION:

Agflroved uncongi{iong1|y

CONDITIONS:

NOTE:

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pleese canlac lhe Registrar's o/i»oe • • Nicoleen.Po:giete«@wi s.ac.za>

SUP EfiYISOfi:

Ms K Mashola

APPROVED BY:


Dr CB Penny, Chairperson, HREC (Medical)

DATE OF APPROVAL:

2023/04/04

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATOR

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Appendix Q: Turnitin report

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ORIGINALITY REPORT

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