REHABILITATION PROGRAMME TO ENHANCE COMMUNITY REINTEGRATION FOR PEOPLE LIVING WITH SPINAL CORD INJURIES IN RURAL AREAS OF LIMPOPO PROVINCE – SOUTH AFRICA

by

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THESIS

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DEDICATION

This thesis is dedicated to my late elders – my father, Elsayed Ellaithey, my father-in-law, Hussien SidAhmed, and my grandmother, Ballala Osman – who always encouraged me to work hard and reach for the stars. Thank you for all your support and encouragement. I wish you were here to see this in person. May your souls rest in peace (wa rahmakoum Allaha).

DECLARATION

I, declare that this thesis, **REHABILITATION PROGRAMME TO ENHANCE COMMUNITY INTEGRATION FOR PEOPLE LIVING WITH SPINAL CORD INJURY IN RURAL AREAS OF LIMPOPO PROVINCE – SOUTH AFRICA**, hereby submitted to the university of Limpopo, for the Doctoral degree of Health Science has not previously been submitted by for a degree at this or any other university; that is my work in design and execution, and that all material contained herein has been duly acknowledged.

_____ _____

Ehab Elsayed Mohamed **Date**

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ABSTRACT

Background and Purpose

Rehabilitation programmes for PLWSCI aim to give them as much independence as possible and perfect integration at a later stage. Proper rehabilitation involves effective community integration of a person with the SCI. Rehabilitation and community integration are key to return the person with an SCI to play his/her role in the community as an effective, independent, and important person. Globally, PLWSCI are facing numerous barriers and limitations, especially in rural areas, where rehabilitation resources are limited. There is a dearth of rehabilitation centres in the Limpopo Province, which might impact negatively on the rehabilitation and community integration outcomes for PLWSCI in this region. The absence of rehabilitation centres in this province point to the need for the development of extra skills for the professionals who work in the rehabilitation team in this Province.

Aim and Objectives

The overall aim of this study was to develop a rehabilitation programme to enhance community reintegration for PLWSCI in rural areas of the Limpopo Province, South Africa.

Methodology

This study used a convergent parallel mixed method design in phase 1. A mixed methodology approach consists of a set of designs and procedures in which both quantitative and qualitative data are collected, analysed, and mixed in a single study. Quantitative data were generated and collected regarding the rehabilitation and community integration challenges of PLWSCI using the Spinal Cord Injury Community Reintegration Measure (SCICRM) tool. Qualitative data were collected through focus group discussions (FGDs). In phase 2 of the study, the Delphi study design was utilised and conducted as a forecasting method based on the results of phase 1.

Results

Quantitative results show that 37% of the respondents were fully reintegrated. Moderate reintegration was above average (54.4%), while 5.7% were minimally integrated, and 3.9% failed to reintegrate into their communities. The rehabilitation teams' home visits were further rated as "never happened" (51%) and "rarely happened" (14.3%). Patients who received a home visit from their rehabilitation team were more likely to fully reintegrate into their community, in this case, 75%. Of those who did not receive any home visits, only 39% managed to fully reintegrate into their communities.

The qualitative findings, which is based on information-rich interviews with participants, indicated an urgent need for the implementation of a rehabilitation programme to enhance a successful and better community reintegration for PLWSCI. The qualitative results also highlighted the importance of home visits and following up on the patients after they have returned to their communities. The qualitative findings were presented according to six themes that were also divided into several sub-themes.

In phase 2 of this study, experts agreed that the rehabilitation programme to enhance community integration for people with SCIs in the Limpopo Province should include the identification of the rehabilitation team, distribution of powers between the team members, documentation and referral letters, mobility, assistive devices, sub-acute rehabilitation tasks, home programmes, and the outcome of the successful rehabilitation.

Conclusion

Rehabilitation is the bridge between the SCI and successful community integration. A comprehensive rehabilitation programme implemented by a multidisciplinary team should enhance the successful reintegration of PLWSCI.

KEY CONCEPTS

Spinal cord injury; Rehabilitation; Community Reintegration; Program development People Living with Spinal Cord Injuries

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TERMINOLOGY

BARRIER

Macmillan Online Dictionary (2009) defines a barrier as something that prevents progress or makes it difficult for someone to achieve something. For the purpose of this study, barrier is defined as any obstacle that prevents or blocks the process of rehabilitation or community integration.

COMMUNITY INTEGRATION

Salzer and Baron (2006) define community integration as the opportunity to live in the community and be valued for one's uniqueness and ability like everyone else. Mothabeng (2007) defines community integration as being part of a family and community mainstream and being involved in each life situation. Mothabeng's (2007) definition will be used as an ideal definition for the purpose of this study.

DISABILITY

Disability is defined as a physical or mental handicap that has lasted for six months or more or is expected to last at least six months, which prevents the person from carrying out daily activities independently. These daily activities include any social restriction, bodily impairment, and personal activity limitation (World Health Organization [WHO, 2013]. In this study, disability will refer to impairment resulting from spinal cord injuries (quadriplegia and paraplegia).

REHABILITATION

Rehabilitation is defined as a set of measurements that assists individuals who experience disability, to achieve and maintain optimum functioning in interacting with their community (WHO 2011). In this study, rehabilitation will refer to the procedure followed to assist people with spinal cord injuries to maintain optimum functioning and be successfully reintegrated in their communities.

SPINAL CORD INJURY

Spinal cord injury (SCI) is defined as any deficit to the sensory-motor, bladder, and bowel functions (Abrahams, Marks & Hutchings 2003). SCI could happen because of

a sudden, traumatic blow to the spine that fractures, dislocates, crushes or compresses one or more vertebrae. It could also result from a gunshot or knife wound that penetrates and cuts the spinal cord. A non-traumatic SCI could be caused by TB-spine, meningitis, arthritis, cancer, inflammation, infections, or disk degeneration of the spine (Possley, Blair, Freeman, Schoenfeld, Lehman & Hsu 2012).

SPINAL CORD INJURY COMMUNITY REINTEGRATION MEASURE TOOL (SCICRM)

The Community Reintegration Measure (SCICRM) is a tool developed by Maleka (2011) to measure the community reintegration for the people living in the rural areas of Limpopo. The Community Integration Measure (CIM) was developed by McColl, Davies, Carlson, Johnston and Minnes (2001).

CHAPTER ONE

INTRODUCTION AND BACKGROUND

1.1 Introduction

This chapter provides an overview of the rehabilitation related to the community reintegration for people living with spinal cord injury (PLWSCI). The challenges that contributed to unsuccessful community reintegration for PLWSCI in different environments are also discussed. The aims and objectives of the study will also be outlined. The significance of the study elucidates the urgent need for designing an ideal rehabilitation programme to enhance successful community integration for PLWSCI in rural areas of the Limpopo Province in South Africa.

1.2 Background

Spinal cord injury (SCI) implies a drastic change in the quality of life of an individual (Benavente, Palazón, & Alcaraz 2003) and the impact of SCI is devastating to the individual and family (Possley et al 2012). Patients who have had an SCI undergo extensive rehabilitation, as it is extremely important for the long-term well-being of individuals with disabilities (Stuifbergen & Becker 2001). Rehabilitation programmes for PLWSCI aim to give them as much independence as possible and perfect integration at a later stage. Rehabilitation is the healthcare provided to people with permanent or temporary disabilities to help them overcome their disabilities. Proper rehabilitation involves the effective community integration of a person with the SCI (Possley et al 2012). Rehabilitation and community integration are necessary to return the person with an SCI to play his/her role in the community as an effective, independent, and important person (Benavente et al 2003).

Rehabilitation for the patient should start at the hospital and focus on the formulation of a rehabilitation plan, based on functional goals by the level of injury (Forchheimer & Tate 2014). The ideal outcome might not always be achieved for each patient because individual outcomes vary, despite similar

levels of injury (Bick 2011). These variations are related to age, sex, and medical complications. Preparation for discharge is crucial to allow a smooth transition back home.

There have been advances in SCI rehabilitation such as wheelchair technology, functional electric stimulation, and pressure sore prevention technology. Special cars have now also been designed for PLWSCI (Lezzoni, Killeen & O'Day 2006). Advancements in rehabilitation over the past two decades have improved the quality of life of PLWSCI regarding independence, health, and the number of people surviving with an SCI (Charlifue & Gerhart 2004). This situation is enhancing community integration for the increased number of SCI individuals in the community (Krause 2010). This advancement, however, might not necessarily have the same positive outcomes in rural settings such as the Limpopo Province due to the scarcity of rehabilitation centres in this province.

Community reintegration after hospitalisation has emerged as an important goal of rehabilitation, given the current emphasis on cost containment of inpatient care and the need for a decreased length of stay at hospitals (Krause 2010; Tate & Forchheimer 1998). The reintegration of PLWSCI involves re-establishing previously existing roles and relationships and developing new ones (Dijkers 1998). Thus, even if the recently rehabilitated individual with an SCI returns to a home that has been modified for him/her, or to the same career, the utilisation of different resources and services and even different "spheres of influence" might create the need for necessary modification or adjustments to a seemingly "new" community (Charlifue & Gerhart 2004). Finding accommodation that is more suitable could mean moving from a familiar neighbourhood to something new or different (Charlifue & Gerhart 2004).

The community integration process varies, as this process depends on several factors such as the economic status of the patient and the economic situation of the country in general. This affects the availability of the rehabilitation facilities the individual needs, such as physical environment, social factors including culture, the political system, and the healthcare system of the country, and

individual factors such as timing of the injury versus age, severity of the disability, and secondary complications (Lau, Chi & McKenna 1998).

1.3 Research problem

Globally, PLWSCI are facing numerous barriers and limitations, especially in rural areas where rehabilitation resources are limited. In South Africa, the 2011 census (Statistics South Africa 2011) revealed that education and employment opportunities are the main challenges faced by PLWSCI. Disabled persons in Limpopo's rural areas have inadequate access to transport, health, and other basic services, making them vulnerable to the poverty trap and its associated vices (Statistics South Africa 2011). During the 2011 Physiotherapy Forum in Limpopo, people with disabilities were unable to participate in the forum due to the inaccessibility of the venue.

Despite the fact that there is a marked difference between the urban and rural settings in South Africa, there is a dearth of rehabilitation centres in the Limpopo Province, which might impact negatively on the rehabilitation and community integration outcomes for PLWSCI in this region. The absence of rehabilitation centres in this province points to the need for the development of extra skills for the professionals who work in the rehabilitation team in this province. It is the responsibility of the professionals in this province to compensate for the absence of rehabilitation centres and to lead people with SCI to successful community integration. The main intention behind providing rehabilitation is to improve patients' quality of life. In areas where rehabilitation centres are available, many patients could once again carry out their responsibilities properly, were able to live independently, and enjoy quality of life. The establishment of rehabilitation programmes suitable for rural settings, especially post-hospital discharge, would contribute to patients having an improved quality of life.

1.4 Aim of the research

The aim of this study was to develop a rehabilitation programme to enhance community reintegration for PLWSCI in rural areas of the Limpopo Province, South Africa.

1.4.1 Objectives

This research was conducted in two phases. Each phase's aim and objectives are outlined in Table 1.1.

TABLE **1.1:** AIMS AND OBJECTIVES OF THE STUDY

PHASE	**AIM**	**OBJECTIVES**
1	To determine how PLWSCI are integrated with their communities in the rural areas of Limpopo	To describe the challenges facing PLWSCI in rural areas regarding rehabilitation and integration with the community To identify the physical barriers of the rehabilitation for PLWSCI in the rural areas of Limpopo
2	To develop a rehabilitation programme that will enhance community integration for PLWSCI in Limpopo	To design an intervention programme that will enhance community integration, informed by the challenges PLWSCI experience within their rural context

1.4.2 Research questions

Phase 1

What are the challenges faced by PLWSCI regarding rehabilitation and community reintegration in the rural areas of the Limpopo Province?

Phase 2

What are the interventions programmes items that enhancing community integration in rural areas of the Limpopo Province?

1.5 Significance of the research

The significance of this study comprised three components.

1.5.1 Significance of the study to professionals

This study contributed to the body of knowledge on physiotherapy, occupational therapy, psychology, and other fields where practitioners are a part of a rehabilitation team. Understanding the current situation contributes to the development of rehabilitation programmes. The role of these professionals is to develop such programmes. In general, there is shortage of studies on rehabilitation and management of SCI in rural areas in South Africa; the researcher, therefore, endeavoured to bridge this gap.

1.5.2 Significance of the study to disabled people

This study also raised the voice of the disabled person in rural areas in Limpopo, South Africa, as it was the first study in this field and in this region of South Africa.

1.5.3 Significance of the study to the South African community

PLWSCI are a part of the community, and the integration of such people calls for the awareness of his/her needs and expectancy, as well as developing a new lifestyle for the person. The integration of these people requires planned programmes, and the initial step of planning such programmes is research.

1.6 Conceptual framework

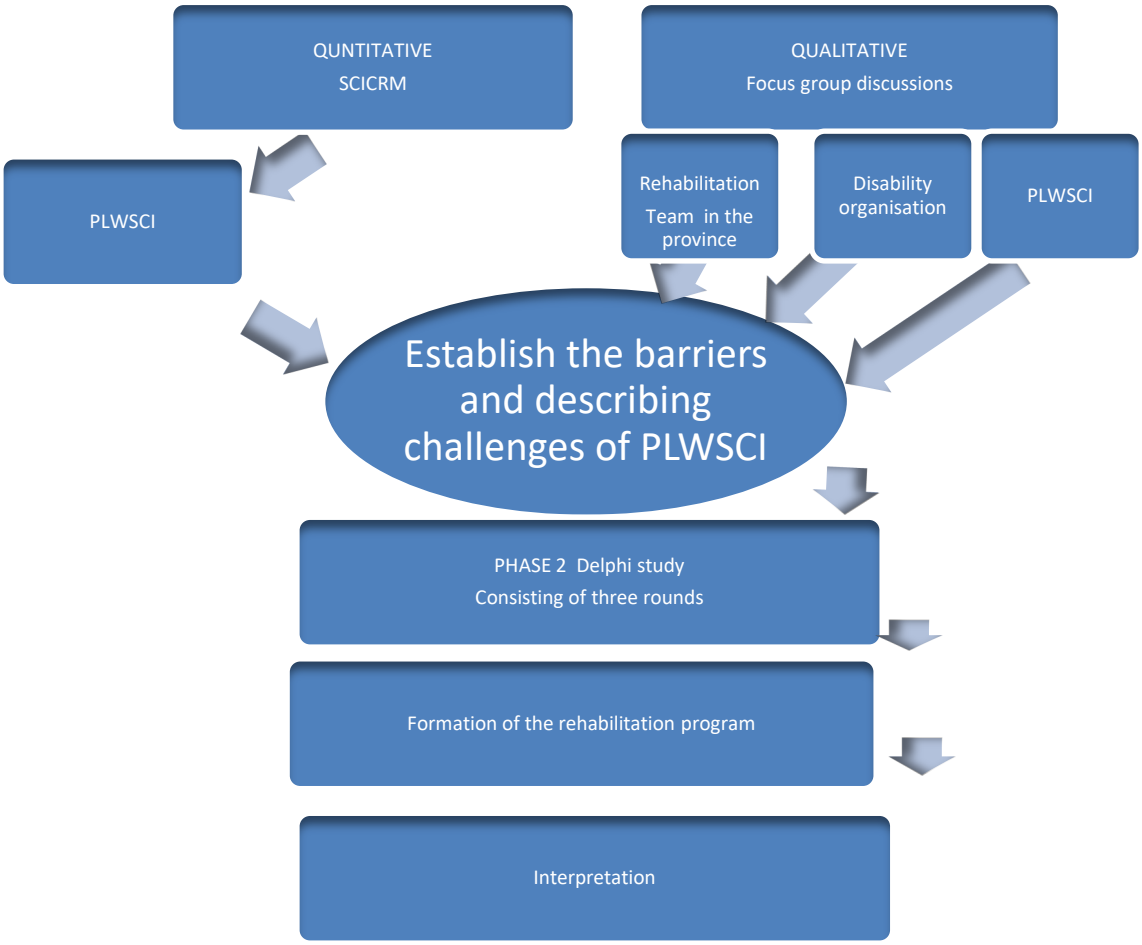

Figure 1.1: Conceptualisation of the research relations

1.7 Theoretical framework

This study applied the Donabedian model as a framework to develop a rehabilitation programme for people living with spinal cord injury in the Limpopo province. The Donabedian conceptual model was developed in 1966 to evaluate the quality of health care (Donabedian 1988; Donabedian 2005). According to the model, information about the quality of care can be drawn from three categories, namely “structure”, “process”, and “outcomes (Donabedian 2005). Donabedian developed his quality of care framework to be flexible

enough for application in diverse healthcare settings and among various levels within a delivery system on the health status of patients and populations (Haiyan, Shewchuk, Chen & Richards 2010).

In this study, the Donabedian model is used to initiate the framework of the rehabilitation programme based on three components, namely the structure, process, and outcome. The structure was represented in the formation of the rehabilitation team and the identification of where and when the programme should be applied. The process was represented by the measurement and the procedure to be followed to apply the programme of the rehabilitation for people living with spinal cord injury in Limpopo. The outcome was represented by outcome indicators to evaluate the success of the rehabilitation programme. The model was also used to form the framework questionnaire, which was presented to the experts in the Delphi study based on the results of phase 1 of this study.

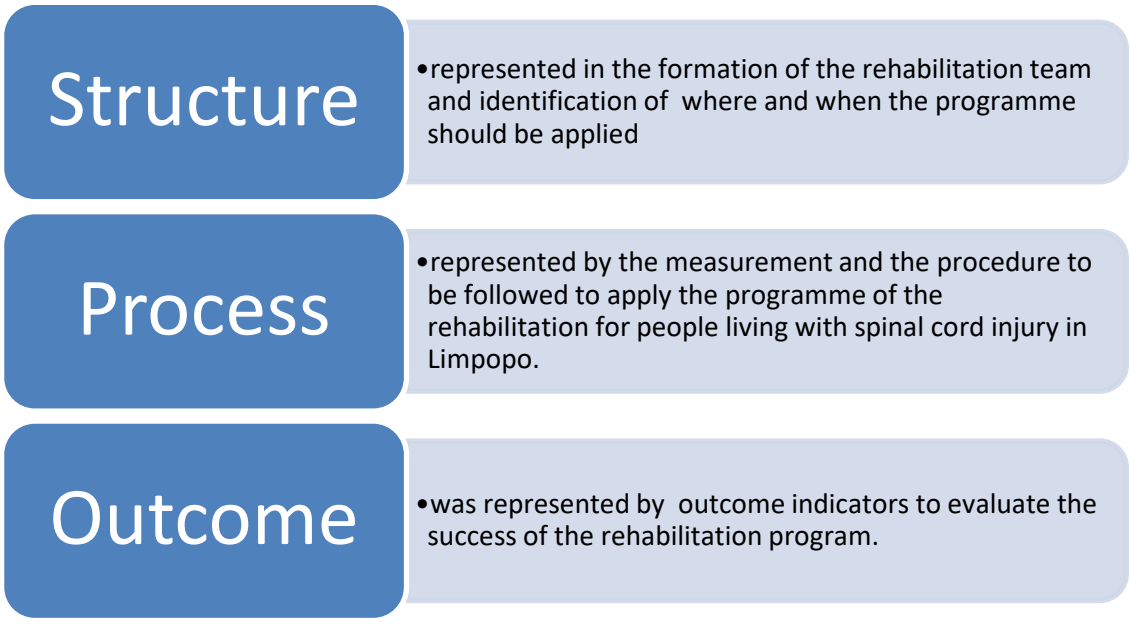

Figure 1.2: Donabedian Framework

1.8 Outline of the study

The chapters of the study are organised as follow:

Chapter 1: The introductory chapter presented a background of the rehabilitation and community integration problems related to PLWSCI. The factors contributing to community integration in different environments were also discussed. The aim, objectives, study questions, and the significance of the study were also presented in this chapter.

Chapter 2: This chapter provides an extensive literature review on the current trends in the prevalence foci, causes foci, challenges of SCI rehabilitation, and stages of SCI rehabilitation with an emphasis on the sub-acute stage. Community integration, community reintegration in rural areas, and the role of the multidisciplinary team in rehabilitation and community integration of SCI patients were also presented. The last part of the chapter discusses the Delphi study technique.

Chapter 3: The methodological methods used in this study, research settings, population, study design, sampling procedure, as well as data analysis is discussed in this chapter. Ethical considerations related to this study are also outlined.

Chapter 4: This chapter contains the results obtained in phase 1 of this study. These results, including the quantitative data analysis results and qualitative thematic analysis of the focus group interviews, are presented and discussed in this chapter.

Chapter 5: This chapter provides details of the steps taken to carry out the Delphi study. The steps in the consensus and recommendations of the experts who participated in the Delphi panel are outlined.

Chapter 6: The last chapter presents the discussion of the results of the various phases of the study to achieve the primary aim of the study. The suggested rehabilitation programme is also presented. This chapter highlights the conclusions, recommendations, and limitations of the study.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

The previous chapter provided an introduction and background to the study. This chapter will review the literature relevant to this study. The literature reviewed on the reintegration of PLWSCI and the rehabilitation of SCI revealed limited research and literature in South Africa. Most of the literature reviewed focused on international studies. In South Africa, most of the literature focuses on the integration of disability in general. The United States (US) is the world leader regarding research, legislation, and the rights of PLWSCI. The literature reviewed on the epidemiology of SCI indicated the global nature of the problem.

2.2 Causes of spinal cord injuries

Motor vehicle accidents (MVAs) are the top cause of SCI (Forchheimer & Tate 2004; Forchheimer & Tate 2014). In South Africa, however, MVAs, gunshot wounds, and domestic violence are the leading causes of traumatic SCI. Tuberculosis of spine rose in the last two decades as a compelling cause for pathological SCI because of the widespread nature of the human immunodeficiency virus (HIV) (WHO 2013).

An SCI might be complete or incomplete. An incomplete injury prevents the ability of the spinal cord to convey messages to or from the brain (Possley et al 2012). People with incomplete injuries retain some sensory function and could have voluntary motor activity below the injury site (Forchheimer & Tate 2004; Forchheimer & Tate 2014; Possley et al 2012).

A complete injury prevents nerve communications from the brain and spinal cord to parts of the body below the injury site (Possley et al 2012). Studies have shown that people with incomplete injuries have a greater chance of recovering some function in the affected limbs than those with a complete injury have

(Possley et al 2012). Complete injury to the spinal cord could lead to permanent disability of the person, while incomplete injury could lead to temporary or partial stroke disability (National Institute of Neurological Disorders and Stroke 2013).

The outcome of any injury to the spinal cord depends on the level at which the injury occurs in the neck or the back and how many and which axons and cells are damaged. The more axons and cells that survive in the injured region, the greater the amount of function recovery (National Institute of Neurological Disorders and Stroke 2013).

Abraham and Brown (2016) studied the causes of SCI and concluded that the most common causes of CSI are motor vehicle collisions (31.5 – 47.6%), falls (21.8 – 40.6%), and violence (5.04 – 14.6%), primarily shootings. Abraham and Brown (2016) compared their results with a recent epidemiologic study and found an increase in SCI resulting from falls between 1997 and 2012; from 19.3% to 40.4%. The increase was most pronounced in the over-65 age group; from 28% (between 1997 and 2000) to 66% (between 2010 and 2012) (Abraham & Brown 2016). The National Spinal Cord Injury Statistical Centre (NSCISC) reported that 80.7% of all reported SCIs occurred in males (Abraham & Brown 2016).

As the average age in the US rises, so does the mean age at the time of injury for PLWSCI. The US Census Bureau predicts that the proportion of Americans 65 years of age and older will increase from 13.7% in 2012 to 20.3% by 2030, and to 20.9% by 2050. The NSCISC calculated that the mean age at the time of injury increased from 28.7 years between 1973 and 1979 to 42.2 years between 2010 and 2014 (Abraham & Brown 2016).

2.3 Prevalence of spinal cord injury

The annual incidence of SCIs worldwide is between 11.5 million cases, which equals 57.8 cases per million people (Ditunno, Patrick, Stineman, Morganti, Townson & Ditunno 2006). It is estimated that in the US, the annual incidence

of SCI is approximately 40 cases per million people. Approximately 243 000 people in the US were alive after accidental SCIs in December 2003 (Forchheimer & Tate 2014; Welage & Liu 2008).

In South Africa, the data collected in the 2011Census (Statistics South Africa 2011; Joseph et al 2016; Pefile, Mothabeng &Naidoo 2019) indicated that there were 2.3 million people with various forms of disability. This number constituted 5% of the total population enumerated in this census. The number of females affected was 1.2 million compared to 1.1 million males (Statistics South Africa 2011). The prevalence increased by age from 2% in the age group 0–9 years, to 27% in the age group 80 years and above. The prevalence of sight disability was the highest (32%), followed by physical disability (30%), hearing disability (20%), emotional disability (16%), intellectual disability (12%), and communication disability (7%). About 30% of disabled people had no education, while only 13% of the non-disabled population fell in this category. Findings provide useful information about the prevalence of disability in the country. The profiles of disability are underscored by the need for preventive and rehabilitation programmes that target the most affected groups (Statistics South Africa 2011).

Disabled persons are considered disadvantaged regarding educational and employment opportunities (Statistics South Africa Stats 2011). Statistics South Africa (2011) collected data on the disability status of the population in the 1996 and 2001 census. A survey was also conducted in the large-scale community in February 2007 using related questions. The measurement of disability was based on the definition of the WHOs (1980) International Classification of Impairments Disabilities and Handicaps (ICIDH), which defined it as a physical or mental handicap that lasted for six months or more or is expected to last at least six months and prevents the person from carrying out daily activities independently (Statistics South Africa 2011: Joseph 2016).

A survey study conducted by Wyndaele and Wyndaele (2006) concluded that there was a need for improving the registration of SCI and the publication of the findings in many parts of the world. This survey pleads for uniformity in

methodology. The data show that the reported incidence and prevalence have not changed substantially over the past 30 years. Data from Northern America and Europe show a higher incidence, but prevalence has remained the same. The epidemiology of SCI seems to have changed during the last few decades with a higher percentage of tetraplegia and complete lesions. If such evolution is present worldwide, how it could eventually be prevented needs to be studied (Wyndaele & Wyndaele 2006).

2.4 Challenges of spinal cord injury rehabilitation

SCIs cause not only damage to the spinal cord and physical function but also cause many complications. The following are frequent complications of SCI: neurogenic bladder, bowel and urinary tract infections, pressure ulcers, orthostatic hypotension, fractures, deep vein thrombosis (DVT), spasticity, heterotrophic ossification, contractures, autonomic dysreflexia, pulmonary and cardiovascular problems, and depressive disorders (Nas, Yazmalar, Sah, Aydin & Öneş 2015). These complications are causally related to the patient's life expectancy and quality of life.

Bladder infections, pressure ulcers, and autonomic dysreflexia especially isolate the patient from society. Negative changes occur in the patient's perception of health due to the complications resulting from SCI. Pressure ulcers, spasticity, contractures, and bladder and bowel problems especially cause a delay of integration with society and psychosocial distress for patients. SCI patients are hospitalised for a lengthy period and experience a variety of limitations in daily living activities due to these complications. Low self-esteem can also occur because of sexual dysfunction, negatively affecting the patient's body image (Nas et al 2015).

During the growth period, diabetes and metabolic diseases are potentially serious diseases in patients who have suffered SCI in childhood. Spasticity, insulin resistance, dyslipidaemia, reduced glucose transfer, and obesity are common childhood complications (Nas et al 2015).

People with SCI require not only initial medical care and rehabilitation but also ongoing access to wheelchair-friendly environments and appropriate home care, equipment, transport, employment, and financial support (Harvey 2016). The management of people with SCI, therefore, is complex, involving many healthcare professionals, organisations, and government services (Harvey 2016).

The challenges faced by PLWSCI differ in developed countries as opposed to low-resource countries (Burns & O'Connell 2012). In developed countries, the capacity to deliver emergency and acute care is immediately provided following an SCI. In many low-resource countries, it is rare for an individual with an acute SCI to be immobilised in the field and transported by trained personnel (Rathore, Hanif, Farooq, Ahmad & Mansoor 2008). In the case of an unstable spine, it can lead to further neurological compromise. A Pakistan study of 83 subjects found that none of the subjects was immobilised at the accident site and only 18 were transported by ambulance.

Delays are common between the initial injury and presentation for specialised care, even when it is available (Rathore et al 2008). One study from India found an average 45-day delay between injury and presentation to a spinal unit, primarily due to a lack of healthcare providers' knowledge that such units existed (Rathore et al 2008). A study conducted in Sierra Leone determined that five to seven patients who died in hospital had been referred from other hospitals with an average delay of 17 days (ranging from 3–42 days) post-injury (Burns & O'Connell 2012). People with thoracic and lumbar injuries in low-resource countries have poorer first-year survival than those with similar injuries in developed countries. People with cervical SCI are even less likely to survive the initial injury and/or hospitalisation in low-resource countries. This is reflected in the few surviving individuals presenting with cervical SCI, compared to the number in resource-rich regions (Burns & O'Connell 2012).

The situation in South Africa is much better compared to other African countries. Patients are most likely to receive proper transportation by ambulances in most South African regions (Joseph, Rhoda, Mji, Statham,

Mlenzana & De Wet 2013). The public-funded healthcare system in South Africa cares for approximately 80% of South African citizens and provides general care to survivors of SCIs (Joseph 2016).

There are only two appropriate units in the Western Cape Province; one for acute cases and one for rehabilitation. However, not everyone who sustains an SCI is accepted to be managed in these units due to resource constraints, and therefore prioritised according to injury severity. This criterion leaves a group of injured individuals to be managed at facilities that do not have the full organisational capacity to handle the complexities of the injury (Joseph et al 2013).

Rehabilitation as an integral part of healthcare services has been neglected in South Africa, with no disease-specific policy plans outlining quality indicators (Joseph 2016). A starting point, however, for the discourse on rehabilitation is South Africa's own National Rehabilitation Policy that emphasises equal opportunities, the ability to participate socially, and integration back into society (Joseph et al 2013). Similar to the resource constraints limiting access to acute spinal cord injury care, rehabilitation is also judged on an individual basis by considering potential recovery and other demographic factors (Joseph 2016). Joseph et al, (2013) found that persons with complete SCI who improved their functional abilities were discharged (80.3%) without follow-up appointments and have been judged by a multidisciplinary team to be at a level of societal integration following rehabilitation. More research is needed to better inform rehabilitation services for PLWSCI by providing evidence to support the need for life-long rehabilitation (Joseph 2016).

2.4.1 Medical management and secondary complications

Pressure ulcers are a major cause of morbidity and mortality in resource-poor environments (Burns & O'Connell 2012). In the Pakistan study, 33 (39.7%) out of 83 individuals had pressure ulcers at rehabilitation admission (Rathore et al 2008). In a Nigerian study, 60% of individuals with SCI developed pressure ulcers during their initial hospitalisation (Obalum, Giwa, Adekoya-Cole &

Enweluzo 2009). In comparison with these observations from developing nations, a study utilising data from the American National Spinal Cord Injury Database revealed a pressure ulcer prevalence of 11.5% a year post-injury, increasing to 21% 15 years post-injury (Burns & O'Connell 2012).

2.4.2 Medical equipment

Prescribed equipment needs to be practical, durable, and reparable, ideally by the injured individual or family. If the self-repair of equipment is not practical, the injured individual should have an identified local resource to access for equipment-related issues; otherwise, it is common for still-useful equipment to be discarded (Burns & O'Connell 2012).

Rathore, Mansoor and Qureshi (2012) commented on the study conducted by Burns and O'Connell (2012). They added that SCI rehabilitation is a poorly understood concept for most healthcare professionals involved in SCI care in Pakistan. For the majority, rehabilitation is "some form of exercise", rather than a multidisciplinary team approach. Others considered a complete SCI not worthy of any active management and rehabilitation (Rathore et al 2012).

2.4.3 Patient counselling and explanation of prognosis of a disease is inadequate in some countries

Patient counselling and an explanation of the prognosis is a major contributing factor towards inadequate outcomes for the majority of the SCI patients in low-income countries in Asia (Rathore et al 2012). Many of the consequences associated with SCIs do not result from the condition itself, but from inadequate medical care and rehabilitation services, and from barriers in the physical, social, and policy environments (WHO 2013).

Irshad, Mumtaz and Levay (2011) found that the main interest of most patients with a low educational level was "their ability to walk again". This results in patients going from one place to another in search of a cure for the SCI. The cures offered and attempted by the patients in Pakistan include stem cell transplants (from China), ozone therapy, hyperbaric oxygen therapy, alternative

and complementary medicine (including Ancient Greek and Arabic medicine, homoeopathy, and acupuncture) along with spiritual healing (Irshad et al 2011). Despite all these limitations in SCI care in some countries such as Pakistan, a few PLWSCI attempt community reintegration and independent mobility, but they are confronted by the negative attitudes prevalent in society (Rathore et al 2012).

2.5 Stages of rehabilitation of people living with spinal cord injury

Scientist in the field of rehabilitation divided the rehabilitation for PLWSCI into three stages, namely (1) acute, (2) sub-acute, and (3) chronic (Nas et al 2015). The acute rehabilitation stage begins with admission to hospital and stabilisation of the patient's neurological state. This stage usually takes between 6–12 weeks. Professionals call this stage the bed-stage (Diong et al 2012). The aim of rehabilitation in this period is to prevent complications that might occur in the long term. The most common and important complication is the development of joint contractures and stiffness during this period. At least one joint contracture (43% shoulder, 33% elbow, 41% forearm and wrist, 32% hip, 11% knee, and 40% foot and ankle) has been reported in approximately 66% of patients within one year if the patient is paraplegic or tetraplegic (Diong et al 2012).

Diong et al.'s (2012) study showed the importance of early engagement of the rehabilitation team in the acute stage of the SCI. This early engagement should include the whole rehabilitation team, each in his/her profession. The rehabilitation in this stage must be shared with patients and their relatives (Nas et al 2015).

2.5.1 Rehabilitation of acute stage of spinal cord injury

Recent studies have shown that early mobilisation plays a significant role in the prevention of pulmonary function decline and the development of muscle strength. Breathing exercises should be carried out and taught, and its importance should be explained to complete or incomplete paraplegic and

tetraplegic patients during the acute phase to protect lung capacity (Nas et al 2015).

The treatment of acute cases of SCI requires the treatment of the medical and physiological consequences of the injury (Emerich, Parsons & Stein 2012; Nas et al 2015). Comprehensive rehabilitation services must include a highly specialised interdisciplinary approach that addresses the medical, physiological, functional, psychological, and social issues (Emerich et al 2012). The goal of the rehabilitation team in this stage is to recognise the needs of the SCI patient and implement interventions to maximise patient outcomes (Emerich et al 2012).

Team members should understand the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) as well as the relationship of these standards to the prognosis for recovery and anticipated functional outcomes that impact activities of daily living (ADLs) and functional mobility (Furlan, Bracken & Fehlings 2010). It is important during the acute phase of rehabilitation to address the psycho-social impact of SCI and to address issues of adjustment (Furlan et al 2010). The team must be able to implement complex discharge plans and arrange for life-long follow-up and health promotion.

Communication and collaboration among team members are crucial for the successful rehabilitation of PLWSCI (Emerich et al 2012). Equally important is the feedback that nursing staff provide to their teammates regarding the patient's ability to carry over these skills during evening hours. Nursing staff often have interactions with family members that are of immense value to other team members, allowing all members of the team to adjust their treatment goals and strategies, as necessary. The patient's family support is crucial, and the family should be part of all the decisions concerning the patient's treatment. There are a variety of ways to communicate and collaborate, including team meetings, family conferences, and group sessions (Emerich et al 2012; Furlan et al 2010).

2.5.2 Rehabilitation of sub-acute stage of spinal cord injury

The sub-acute stage of rehabilitation is where all members of the rehabilitation team must engage with the patient to prepare him/her to be discharged from the hospital (Diong et al 2012; Nas et al 2015; Schwartz, Sajina, Neeb, Fisher, Luerer & Meiner 2011). Schwartz et al (2011) discussed the importance of using technology in the sub-acute phase of rehabilitation. The authors employed locomotor training (using a robotic device) in patients with sub-acute SCI. Regardless of the technology used in the sub-acute stage; it is the stage of mobilisation out of bed. At the end of the sub-acute stage, a patient should be able to sit and stand and is prepared to transfer and balance (Schwartz et al., 2011). Diong et al (2012) reported that in the sub-acute stage, patients usually presented with orthostatic hypotension or syncope while sitting or standing. These incidents occurred due to low blood pressure. Low blood pressure usually develops due to the lengthy periods of lying in bed during the acute stage (Diong et al 2012).

The purpose of rehabilitation in this stage should focus on stability and strength education for sitting and transportation. Functional goals must prepare the patient for movements such as sitting up in bed or a wheelchair, dressing, and transfers. Initially, the goal is successful bed movements. Patients who can tolerate sitting can start to push themselves up with the aid of static and dynamic balance training to transfer themselves to the wheelchair (Schwartz et al 2011).

Wheelchairs, walkers, and crutches are used for out-of-bed transferring of patients. The wheelchair is the most crucial tool for SCI patients to be mobile and participate in social life. Ideally, wheelchairs must allow for optimal mobility, protect skin integrity, and maintain the normal anatomical posture. A battery-assisted wheelchair is appropriate for injuries of the upper segments, whereas a manual wheelchair is preferred for lower level injuries. Wheelchair dimensions such as the height, pelvic width, seat length, backrest, and seat and arm support should be specifically prescribed for each patient (Schwartz et al 2011).

2.5.3 Rehabilitation of chronic stage of spinal cord injury

The final stage of rehabilitation is the chronic rehabilitation stage. The most important goal in this sage is the realisation of the independent mobilisation for both complete and incomplete paraplegic patients during the chronic period (Nas et al 2015). Assistive devices are important for providing chronic stage ambulation. Patients with pelvic control can walk with orthotics or crutches (Schwartz et al 2011). If the muscle strength of the pelvic floor is normal, patients can walk with elbow crutches and orthotics without needing a wheelchair. However, the devices with advanced technological features are also more expensive. Oxygen consumption, energy expenditure, and walking speed can vary significantly depending on the shape, type, and weight of the material of devices used by the patients (Schwartz et al 2011).

The most important expectations in the chronic phase or “phase to return home” are ensuring the maximum independence related to the level of the patient’s injury, integration of the patient into society, and teaching the importance of the family’s role (Baslo 2013). In addition, house modifications are important for PLWSCI to have independent ADL. The door width should be 81.5 cm for manual wheelchair access and 86.5 cm for battery-assisted wheelchairs. The height of electric switches should be 91.5 cm. Adequate insulation and heat must be provided at home. Door handles must be “leverage-shaped”, and the height of the door sills should not impede the passage of a wheelchair for tetraplegic patients. Carpets should be removed, and the surface should be hard to manoeuvre the wheelchair with ease. Bathtubs should be mounted on the wall and must have handles. The height of kitchen apparatuses should be accessible to the patient. There must also be a ramp at the entrance to the house (Baslo 2013).

One of the key features of this period is restoring the patient’s psychological and emotional state because of the high incidence of depression in patients during the first six months (about one in three patients) (Lee & Mittelstaedt 2004). Depression is not a natural process experienced after SCI but a

complication that needs to be treated. Suicide is the most common cause of death after SCI among patients under the age of 55.

The frequency of posttraumatic stress disorder (PTSD) is 17% and usually occurs in the first five years. Consultation with a psychiatrist is needed if the patient presents with psychotic behaviour and depression (Lee & Mittelstaedt 2004). Occupational therapy and finding the patient's role in society are the most crucial factors for restoring the patient's psychological state. Social and psychological problems in the absence of daily activities have been reported. Suicide attempts have also been reported due to a lack of daily activity, depression, alcohol dependence, and emotional distress. Occupational therapy allows SCI patients to be more social, to use their own functions for creative jobs, and to deal with psychological problems such as depression (Lee & Mittelstaedt 2004).

2.6 Community integration

Community integration received considerable attention in the studies carried out by professionals in the field of rehabilitation in South Africa. Mothabeng (2007) conducted a study on community participation for PLWSCI in the Tshwane Metropolitan area. The study aimed to explore the challenges of community integration in Gauteng, which is considered an urban area in South Africa. The study revealed three factors influencing community integration, namely disability-related factors, personal factors, and environmental factors. Employment and environmental factors were found as the main barriers to successful community integration of PLWSCI. Mothabeng (2007) used a mixed research methodology to conduct the study.

Maleka (2011) carried out a qualitative study about the experience of living with a stroke in a low socio-economic area of South Africa (Limpopo). In this study, Maleka (2011) aimed to conceptualise community reintegration from the perspectives and context of people living in low urban and rural socio-economic areas of South Africa. Maleka's (2011) study concluded that the loss of mobility, social isolation, loss of a role in the family or community, loss of meaningful

activities, threat to livelihood, and loss of hope were the main obstacles to successful reintegration. The author suggested that the assessment of stroke survivors should indicate these activity limitations and participation restriction issues to holistically rehabilitate and successfully reintegrate the patients.

Oliver (1993) pointed out that globally, people with disabilities, including those with SCI, historically have been and continue to be marginalised members of society and their opportunities for participation and community integration is therefore compromised. Studies in Australia showed that poor continuity of care could have significant physical and psycho-social implications for PLWSCI and their families (Forchheimer & Tate 2014). PLWSCI often have limited financial resources to engage in social activities, and they suffer from social exclusion (Kendall et al 2003).

According to Chan and Chan (2013), PLWSCI in Hong Kong stayed in the hospital much longer compared to many other countries. They pointed out that the longer length of stay was due to extensive time required for home modification, equipment prescription, and to prepare for home and community integration. Disability organisations in Sri Lanka reported that buildings, including railway stations and even hospitals, were inaccessible to their members (Chan & Chan 2013).

An important barrier to full community participation was noted by Charlifue and Gerhart (2004). The authors cited barriers such as physical independence, mobility, occupation, social integration, and economic self-sufficiency, limited community resources, and access to medical and social services needed by people with disabilities to live in the community (Charlifue & Gerhart 2004). The transition from acute rehabilitation to home is critical because people are confronted with many obstacles as they attempt to resume participation in their community (Charlifue & Gerhart 2004).

The need for exercise in the SCI population has been well recognised and does not vary dramatically from the general population (Kirshblum, Priebe, Ho, Scelza, Chiodo & Wuermser 2007). PLWSCI are on the lowest end of the

fitness spectrum, and people with paraplegia, despite having more ability and opportunity for physical fitness, are only marginally more fit than those with tetraplegia (Kirshblum et al 2007).

Sedentary lifestyles in those with SCI are thought to contribute to numerous abnormal metabolic and fitness parameters. After SCI, the decreased baseline energy expenditure can contribute to weight gain and obesity (Kirshblum et al 2007). Twenty-two per cent of people with SCI had diabetes compared with 6% of able-bodied controls; 34% had glucose intolerance compared with 12% in a control group. Numerous barriers confront people with SCI as they consider becoming more physically active. Only 8% of fitness facilities were found to provide adequate accessibility to people with disabilities. PLWSCI have also expressed concerns over lack of experience of employees at fitness facilities, lack of privacy, and fear of injury as barriers to activity. Moreover, physicians have recommended physical activity to less than half of those with SCI. These items leave a tremendous opportunity for health professionals involved in the care of people with SCI who need continuous exercise to improve participation in recreation and fitness activities (Kirshblum et al 2007).

2.7 Community reintegration in rural areas

A United State study revealed an unequal distribution of resources throughout the community, which caused difficulties to PLWSCI in rural areas of the US, especially regarding accessibility, transportation, and social participation (Charlifue & Gerhart 2004). Hall, Bushnik, Lakisic-Kazazik, Wright and Cantagallo (2001) pointed out that in rural areas in the US, lack of transportation, physical and architectural barriers, diminished availability, and inaccessibility of healthcare pose significant barriers to people with SCI as they attempt to obtain adequate healthcare and live independently. Gontkovsky, Russum and Stokic (2009) supported this finding by stating that “in the USA, transportation throughout the community was an incredible challenge for persons with SCI, and it was the reason why they were often restricted to their homes.”

Living in an urban area, however, does not necessarily alleviate all potential problems that interfere with successful community integration (Charlifue & Gerhart 2004). If an individual was living in a community where the environmental conditions (such as violence) played a role in the injury in the first place, a return to that community might not be the optimal choice (Adkins, Hume, Nabor & Waters 1998).

Rural environments, on the other hand, could be more limited and non-personal but could be richer in terms of interpersonal support systems (Charlifue & Gerhart 2004). People with disabilities who live in rural communities face complicated challenges in obtaining productive employment that pays a living wage (Carstensen 2008). The high unemployment rate for people with disabilities in rural communities is associated with a variety of factors that remain constant in each rural geographic region (Carstensen 2008). The location (rural or urban) has a significant meaning for PLWSCI regarding their opportunities for community integration, depending on the settings and the resources of the community in that location (Charlifue & Gerhart 2004).

People living with disabilities (PLWD) in rural regions have lower employment rates, less secure employment, and suffer higher rates of poverty (United States Department of Labor 2011). PLWD in rural areas experience frequently inaccessible services and infrastructure (Carstensen 2008), and have fewer advanced education supports than their counterparts without disabilities do (Burns & O'Connell 2012).

PLWD have limited emergency response and less access to preventative and primary medical care, emphasising the importance of addressing the needs of PLWD in rural areas (Lezzoni et al 2006). Many PLWD in rural areas already own homes through inheritance, but they do not have modifications, assistive technology, or the vehicles necessary to function optimally at work and at home (Grinstein-Weiss & Curley 2003; Putnam & Tang 2005). Although PLWD can and do want to acquire assets to facilitate increased independence (Gates, Akabas & Zwelling 2001), there is evidence that PLWD perceive health care,

homes, and businesses as less accessible to them in rural communities than in urban settings (Lezzoni et al 2006).

The research in this area is equivocal. Studies of individuals with intellectual disabilities, for example, lend inconsistent support to this contrast between rural and urban settings (Bramston, Bruggerman & Pretty 2002). Conversely, other studies have suggested that social support might be less available to rural individuals due to their living in isolated environments (Hoffman, Meier & Council 2002).

Regardless of urban or rural settings, rehabilitation and community integration are of the utmost importance to PLWSCI. Although there have been great advancements in the manufacturing of assistive devices for PLWSCI, much more needs to be done to assist PLWSCI. A few countries have given attention to the accessibility measurement for PLWSCI. There is a scarcity of research and investigations on the community integration for PLWSCI in South Africa. This study aimed to bridge the gap in the research on the successful community integration for this important segment of the community in South Africa.

2.8 The role of a multidisciplinary team in rehabilitation and community integration of spinal cord injury patients

The multidisciplinary team in the rehabilitation of SCI patients should include different professionals from healthcare and social sectors, depending on patients' needs (Petrova, Nenova, Mihov, Dobrilov & Kostadinova 2015). Petrova et al (2015) presented the role of a multidisciplinary team in the implementation of integrated care for patients post-surgery to the surgical osteoarthritis cases. Petrova et al (2015) reported that care provided by a multidisciplinary team assisted in the improvement of activity after surgical intervention, functional abilities, psychological, and social health. Integrated provision of multidisciplinary care should be connected to a systematic evaluation of every aspect of the health status of the patient by different healthcare professionals and team planning of the procedures the patient needs (Petrova et al 2015).

The team approach for SCI rehabilitation should be unique for each patient (Petrova et al 2015). Because each injury is so unique, the best treatment options have to be just as unique. The rehabilitation team should comprise experienced doctors, nurses, and therapists who implement active, individualised care plans that concentrate on improving a patient's functionality and mobility. A team approach helps the patients to gain more than mobility; they help the patient to gain greater independence and confidence to help them reach their recovery goals (Lezzoni et al 2006). A team approach for SCI patients achieves a higher quality of life and matches expertise and dedication with a non-institutional, community-based environment that is designed to promote emotional well-being and physical comfort (Tempest, Harries, Kilbride & De Souza 2013).

In the last two decades, research focused on the process of team care rather than results (Tempest et al 2013). The rehabilitation process must have team measures that lead to increased patient participation in the process and is a good indicator of the results. Both Tempest et al (2013) and Petrova et al (2015) focused on the rehabilitation process for patients in post-surgical cases, but their experience can still be presented and considered in the rehabilitation of SCI.

2.9 The Delphi technique

The Delphi technique is a widely used and accepted method of gathering data from respondents within their domain of expertise. The technique was designed as a group communication process that aims to achieve a convergence of opinions on a specific real-world issue (Hsu & Sandford 2007). The Delphi technique was developed by Olaf Helmer and his associates at the Rand Corporation in the early 1950s when they were working on defence research (Yousuf 2007).

Hasson, Keeney and McKenna (2000) described Delphi's development in five stages, namely (1) secrecy and obscurity, (2) novelty, (3) popularity, (4) scrutiny, and (5) continuity. The first stage was secrecy during which the Delphi

technique was classified by the military. Delphi techniques were developed to gain consensus within a group of military experts on a sensitive issue. This stage lasted from the early 1950s to the early 1960s when it was declassified.

The second stage, novelty, lasted from the mid-1960s to the late 1960s. During this stage, the technique was used primarily by corporate planners as a forecasting tool for industry and human services. The third stage, popularity, lasted from the late 1960s to the mid-1970s. During this time, various articles, Delphi technique papers, reports, and dissertations appeared on the topic. The fourth stage, scrutiny, commenced in 1975 with Sackman's unexpected attack on the Delphi technique itself, which was challenged. The fifth and final stage, continuity, is Delphi's present stage of development (Yousuf 2007).

The Delphi process has been used in various fields of study such as programme planning, needs assessment, policy determination, and resource utilisation to develop a full range of alternatives, explore or expose underlying assumptions, as well as correlate judgments on a topic spanning a wide range of disciplines (Hsu & Sandford 2007). The Delphi technique is well suited as a method for consensus-building by using a series of questionnaires consisting of multiple iterations delivered to collect data from a panel of selected subjects (Hsu & Sandford 2007).

In general, the literature summarises that the Delphi technique can be used for achieving the following objectives:

1) To determine or develop a range of probable programme alternatives;
2) To explore or expose underlying assumptions or information leading to different judgments;
3) To seek information that might generate a consensus on the part of the respondent group; and
4) To correlate informed judgments on a topic spanning a wide range of disciplines (Altschuld 2003; Hsu & Sandford 2007; Worthen & Sanders 1987).

Worthen and Sanders (1987) state that this “interactive procedure can continue for several more rounds, but the payoff usually begins to diminish quickly after the third round” (Yousuf 2007).

Methodologists identified several steps involved in using the Delphi technique:

1) Identify the panel of experts.

2) Determine the willingness of individuals to serve on the panel.

3) Gather individual input on the specific issue and then compiling it into basic statements; analysing data from the panel.

4) Compile information on a new questionnaire and sending it to each panel member for review.

5) Analyse the new input and returning the distribution of the responses to the panel members.

6) Ask each panel member to study the data and evaluate their position based on the responses from the group (Yousuf 2007). When individual responses vary significantly from that of the group norm, the individual is asked to provide a rationale for their differing viewpoint while limitations are placed on the length of the remarks to keep responses brief.

7) Analyse the input, and sharing the minority supporting statements with the panel. Panel members are again asked to review their position and if not within a specified range, to justify the position with a brief statement.

Statistical analysis can ensure that the opinions generated by each subject of a Delphi study are well represented in the final iteration because “at the end of the exercise, there may still be a significant spread in individual opinions” (Hsu & Sandford 2007). That is, each subject would have no pressure, either real or perceived, to conform to another participant’s responses that might originate from obedience to social norms, customs, organisational culture, or standing within a profession.

Regarding data analysis, decision rules must be established to assemble and organise the judgments and insights provided by Delphi subjects. The type of criteria to use to both define and determine consensus in a Delphi study is, however, subject to interpretation. Consensus on a topic can, therefore, be decided if a certain percentage of the votes falls within a prescribed range (Yousuf 2007).

The major statistics used in Delphi studies are measures of central tendency (means, median, and mode) and level of dispersion (standard deviation and inter-quartile range) to present information concerning the collective judgments of respondents (Yousuf 2007). According to Hsu and Sandford (2007), the weaknesses of the Delphi technique are subject selection, timeframes for conducting and completing a study, the possibility of low response rates, and unintentionally guiding feedback from the respondent group. These are all areas that should be considered when designing and implementing the Delphi technique.

Adams (2001) reiterates this precaution about the Delphi technique. Altschuld (2003) mentions that low response rates, unintentionally guiding feedback, and surveying panellists about their limited knowledge of the topic rather than soliciting their expert judgments should also be built into the design and implementation of the study. The Delphi technique has and will continue to be an important data collection methodology with a wide variety of applications and uses to gather information from those who are immersed and embedded in the topic of interest and can provide real-time and real-world knowledge (Altschuld 2003).

2.10 Summary

This chapter gave an evaluation of the literature regarding the global prevalence of SCIs, causes of SCIs, challenges of SCI rehabilitation, and rehabilitation stages of PLWSCI with special emphasis on the sub-acute stage. Community integration, community reintegration in rural areas, and the role of a multidisciplinary team in rehabilitation and community integration of PLWSCI

was also presented. The chapter concluded with a discussion of the Delphi technique. The findings of the literature review, therefore, can be summarised as follows:

- SCI has increased worldwide. There is an improvement in the management and rehabilitation methods that should affect better community integration for PLWSCI.

- There is variation in the survival rate, rehabilitation methods, and successful community reintegration for PLWSCI between low-income countries and developed countries.

- Scientists divided the rehabilitation of PLWSCI into three phases. The most important phase is the sub-acute phase as it occurs before discharge from the hospital.

- Accessibility, transportation, social participation, and education were community reintegration challenges for PLWSCI regardless of urban and rural settings.

It is evident that the rehabilitation of PLWSCI is a combined role of healthcare practitioners. Globally, all successful rehabilitation programmes considered the multidisciplinary model to manage SCI cases. The primary focus of this study was on designing an appropriate rehabilitation programme that suits SCI patients in rural areas of the Limpopo Province in South Africa. The next chapter will discuss the methodology employed to conduct the study.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

The preceding chapter was a literature review of this study. This chapter provides the methodology employed to achieve the objectives of this study. This chapter, therefore, provides a detailed description of the methodology utilised. A detailed description of the research setting, population, sampling, study design, the data collection procedure, and data analysis will also be provided.

3.2 Study setting

This study was conducted in the Limpopo Province, which is South Africa's most Northern Province and is situated within the great curve of the Limpopo River. It is the fifth largest of the country's nine provinces. Limpopo Province takes up 10.2% of the country's land area with a population of 5.4 million people (South Africa Info 2009).

Figure 3.1: Map of the Limpopo Province in South Africa

Source: (South Africa Info 2009)

The provincial Polokwane Mankweng Hospital Complex is the only provincial and referral hospital for SCIs, as the Spinal Cord Unit is based in the Polokwane Hospital. Rehabilitation for PLWSCI is done at the Physiotherapy Department in both hospitals as a joint venture with the Occupational Therapy Department. Patients are seen once a month in each of the hospitals. There was a proposal for an academic hospital that would have included the first public rehabilitation centre for PLWD; however, in 2014, the academic hospital project was transferred to the National Department of Health (Annual Report 2013/2014).

3.3 Study population

In this study, the population for the two phases could be described as follows:

- Phase 1: Comprised PLWSCI who reside in rural areas of the Limpopo Province.

- Phase 2: Included a panel of academic and professional experts who were selected for the Delphi study. An equal number of academic and professional experts (six from each) were selected according to the highest number of years of experience in the field and the highest level of education in the field.

3.4 Study approach and designs

This study utilised a mixed research methodology. A mixed methodology approach consists of a set of designs and procedures in which both quantitative and qualitative data are collected, analysed, and mixed in a single study (Seekamp, Harris, Hall & Craig 2010). Mixed methodology research is used when both quantitative and qualitative data together provide a better understanding of the research problem than either type by itself. It is also used when one type of research is not enough to address the research problem or answer the research questions (Creswell 2008).

This study used a convergent parallel mixed method design in phase 1. The researcher collected quantitative and qualitative data concurrently and analysed the two data sets separately (Creswell 2008). The combinations of qualitative and quantitative methods involve the strengths of both methods to answer research questions (Pasick et al 2009). This approach allowed the researcher to obtain useful results from an initial phase, and it was useful to maximise the amount of data collected in the field (Creswell 2008; O'Cathain, Murphy & Nicholl 2007).

In phase 2 of the study, the Delphi study design was utilised and conducted as a forecasting method based on the results of phase 1. The Delphi methodology is a structured communication method that relies on a panel of experts. The experts answered questionnaires in two or more rounds. After each round, a facilitator provides an anonymous summary of the experts' forecasts from the previous round as well as the reasons they provided for their judgments. Thus, experts were encouraged to revise their earlier answers in light of the replies of other members of their panel. During this process, the range of the answers decreased, and the group converged towards the "correct" answer or consensus, resulting in the stability of the results (Hoffmann, Fischbeck, Krupnick & McWilliams 2007).

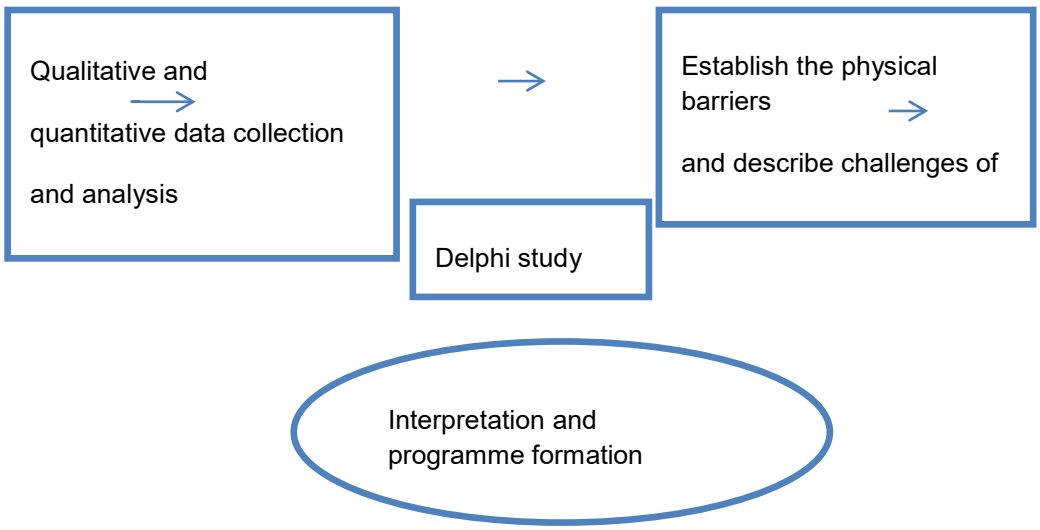

Figure 3.2: Research methodology relations

3.5 Data collection methods and procedure

The data collection for this study will be described for each phase.

During phase 1, qualitative and quantitative data were collected. Qualitative data were collected through focus group discussions (FGDs). The focus group discussions were held at the boardroom in Polokwane hospital, Limpopo province. All the discussions were documented by a video camera. A local professional occupational therapist was present during all the discussions for language interpretations.

Quantitative data were collected from the participants using the Spinal Cord Injury Community Reintegration Measure (SCICRM) tool. The SCICRM tool (questionnaire) has been used by Maleka (2011) in Limpopo province for stroke patients and was developed to suit the SCI patients. A copy of the questionnaire was translated into Sepedi and translated back into English to validate the translation. Participants were interviewed at Polokwane hospital and centenary house depending on the convenience of the participant. This phase entailed gathering information regarding the challenges and physical barriers facing PLWSCI in the Limpopo Province.

During phase 2, the Delphi study was carried out to consolidate and incorporate the results of the mixed methods in phase 1 to shape the rehabilitation programme. Delphi is based on the principle that forecasts (or decisions) from a structured group of individuals are more accurate than those from an unstructured group (Green, Armstrong & Graefe 2007). More details about the Delphi study will follow in chapter five of this study.

3.5.1 Sampling procedure: Phase 1

- Qualitative data

The FGD tool was used to collect qualitative data in phase 1 of this study. Data were collected using two types of discussions.

Type 1: Two groups of professionals were selected from professionals who are involved in the rehabilitation of PLWSCI in the Limpopo Province. The central question posed to the professionals was: “Describe challenges you experience in rehabilitation and reintegration of patients living with spinal cord injury within the rural context”.

Each of these two FGDs comprised six participants (Krueger 2002). A purposive sampling technique was used to select eligible participants. The inclusion criteria used were professionals who were involved in the rehabilitation of SCIs in the provincial Polokwane Mankweng Complex Hospitals. These provincial hospitals are the only referral hospitals in the province that deal with SCI cases.

Type 2: One group of participants was selected for the FGDs of which all of them are PLWD and are working in disability organisations in Limpopo. The central question posed to the group was: “Describe the challenges that the rehabilitation and community reintegration of PLWSCI in rural areas of Limpopo Province face”.

- Formation of focus groups

A focus group is a form of qualitative research in which a group of people were asked about their perceptions, opinions, and attitudes towards a service, concept, idea, or packaging (Krueger 2002). Questions were asked in an interactive group setting where participants were free to talk with other group members (Krueger 2002). Three groups were selected for the FGDs, and each group comprised six participants (because of small numbers). According to Krueger (2002), participants should be carefully recruited and usually includes five to 10 people per group, although six to eight participants are preferred and should be similar types of people.

The FGDs were conducted in a separate room in the rehabilitation areas of the hospital complex. The room was well-lit and quiet. The researcher conducted the interview and guided the discussions by probing when there was a need for further clarity. A video camera was used to capture the discussions, and field

notes were taken to capture unspoken body language or expressions. The focus groups were conducted on different days, which allowed for a debriefing session for the interviewer and the assistant to gain their composure.

- Qualitative data analysis

The analysis of the FGDs started with the transcription of the information from the videotape recording to produce a manuscript. A comparison was then made with the notes taken during the discussion to verify accuracy. Transcribed interview texts were preceded according to discrete steps for inductive, qualitative, and thematic analysis. This process involves the creation of codes, categories, and themes using the following steps (Fischer 2010):

1) Familiarisation: As a first step, all interview transcripts were read several times to make sense of the data as a whole and its key features.

2) Coding: This is an interpretive technique that both organises the data and provides a means to introduce the interpretations of it into certain quantitative methods (Onwuegbuzie & Johnson 2006). Most coding required the researcher to read the data and demarcate segments within it. Each segment was labelled with a “code”, usually a word or a short phrase that suggests how the associated data segments inform the research objectives.

3) Categorising: Various codes are then compared for differences and similarities and sorted into fewer content-related categories with sub-categories describing their different dimensions or characteristics.

4) Themes: Finally, categories were organised into themes that reflect the underlying meaning that can be extrapolated from the data. A theme is considered a thread of meaning that recurs throughout the data on a more interpretative level. Themes attain their full significance when they are linked to form a coordinated picture or an explanatory model.

- Quantitative data

The target population is very small; therefore, a convenience sampling technique was employed to generate the statistical data needed for the analysis from the available target group, namely PLWSCI residing in rural Limpopo. The inclusion criteria designed for this purpose further targeted PLWSCI residing in rural areas of Polokwane. These patients received rehabilitation on two Tuesdays every month at the two spinal cord rehabilitation centres in the Pietersburg and Mankweng hospitals. Furthermore, an additional 15 respondents were to be included from Centenary House in Polokwane, which accommodates PLWD from various parts of Limpopo. Due to the closure of the spinal cord rehabilitation centre at the Mankweng hospital, all available 35 SCI patients, 20 from the Pietersburg spinal cord rehabilitation centre, and 15 from Centenary House were interviewed using the developed SCI community integration measure (SCICIM) questionnaire.

- Selection of the quantitative data collection instrument

The questionnaire was developed from the community integration measure (CIM) Designed by McColl, Jacoby, Thamos, Soutter et al (2001), and the Community reintegration measure CRM (Maleka 2011). Permission to use the CIM and SCICRM measures were freely obtained from the developer through their website. The developed measure included the nine indicators that should be evaluated to determine the level of community reintegration (McColl et al 2001). The nine indicators that are used to determine the content of the questionnaire were as follow:

1) Section A: Demographic data of the patient

2) Section B: Orientation (five questions)

3) Section C: Acceptance (four questions)

4) Section D: Conformity (five questions)

5) Section E: Close and diffuse relationships (six questions)

6) Section F: Living situation, work, and education (five questions)

7) Section G: Independence (five questions)

8) Section H: Productivity (five questions)

9) Section I: Leisure (five questions)

10) Section J: Rehabilitation (four questions)

- Quantitative data analysis

Maleka (2011) developed a four-point scale to judge whether a given patient with a physical disability integrated well with the community he/she lived in after being injured. Maleka (2011) suggested the following scoring scheme:

Happenings of the event	**Score (Value)**
Never happens	0
Rarely happens	1
Sometime happens	2
Always happens	3

Total scoring was 44 x 3 = 132

Patient score = total score／132 x 100%

The scores can be used to determine and interpret the proportion (percentage) of patients opting for each score for the same happening. They can also be used to determine an average score percentage out of the expected total under “always happens”. Maleka’s (2011) method sets a norm to determine whether a given patient reintegrated well into the community based on the average percentage scores. Results are interpreted to provide feedback to the patients and for professional judgment by placing the patients’ scores on the following scale.

An average score of:

- 80% and above indicates full reintegration;
- 60% to 79% indicates moderate reintegration;
- 41% to 59% indicates minimal reintegration; and
- 40% and below indicates no reintegration.

The developed questionnaire was also translated into Sepedi. Sepedi is the most common language spoken by the majority of the population in the province. English was well known and the most understandable language in the province (South Africa Info 2009). An academic specialist translated the responses in Sepedi to English.

All the data gathered were entered into a Microsoft Excel spreadsheet and transported for analysis using the Statistical Package for Social Sciences (SPSS) v22.0. The frequency distribution was calculated. Additionally, inferential statistics were calculated, and associations were determined using Chi-square. The results that were used to develop a rehabilitation programme that has all the components were found from both the qualitative and quantitative components of phase 1 of the study.

3.6 Validity

According to the fundamental principle of mixed research, it should involve a combination of quantitative and qualitative methods, approaches, and concepts that have complementary strengths and non-overlapping weaknesses (Onwuegbuzie & Johnson 2006). In mixed methods research, due to the association with the quantitative conceptualisation of the research process, the term “validity” has generally been replaced by the term “trustworthiness” within qualitative research (Onwuegbuzie & Johnson 2006). Regardless of the strengthening points of the methodology, this research focused on the validity of the data collection instruments.

There are several types of validity, for example, face predictive, content, construct, and concurrent validity (Cohen, Manion & Morrison 2007). This study

focused on face and content validity to validate the research instrument. The questionnaire was made as simple and as clear as possible. To ensure that all areas of the research were covered, each question in the questionnaire was related to the objectives of the study.

Content validity in this study was enhanced by submitting the questionnaire to the researcher's supervisors, who are content experts and examined all possible questions. The questionnaire, therefore, was pre-validated tools that were designed and tested in the South African context, and therefore, were used as is.

3.7 Reliability

Reliability refers to the consistency of a measure. A test is considered reliable if the same result is produced repeatedly. Reliability can be estimated in numerous ways, such as test-retest reliability, inter-rater reliability, parallel-forms reliability, and internal consistency reliability. In this study, test-retest reliability was administrated to achieve reliability (Shuttleworth & Wilson 2009).

The test was administered twice at two different points in time. This type of reliability was used to assess the consistency of a test across time. This type of reliability assumes that there was no change in the quality or constructs being measured. Test-retest reliability is most appropriate for things that are stable over time, such as intelligence. In general, reliability was considered higher when little time has passed between tests (Masedo, Hanley, Jensen, Ehde & Cardenas 2005). In this study, the questionnaire was piloted using selected participants from Centenary House to ensure that the questions were not misinterpreted or that participants react differently each time they take such a test.

3.8 Triangulation for the qualitative aspect of the study

Triangulation is a powerful technique that facilitates validation of data through cross-verification from two or more sources. It refers to the application and combination of several research methods in a study of the same phenomenon

(Bogdan & Biklen 2007). Triangulation creates more confidence in a result if different methods lead to the same result. In this study, triangulation was achieved through the quantitative assessment of community reintegration and related factors measured, combined with cross-verification of the results of the three FGDs, observations, and use of experts.

3.9 Trustworthiness for the qualitative aspect

Trustworthiness in qualitative research refers to the manner in which researchers ensure that transferability, credibility, dependability, and conformability were present in their studies (Bogdan & Biklen 2006).

3.9.1 Credibility

The researcher allowed participants to express themselves as they understood the questions to promote credibility, ensuring that the environment where the interview was conducted had uncompromised privacy and was conducive to a quality interview process. The researcher allowed the participants to raise any concerns about the interviews. To reinforce the findings, the researcher used triangulation (including observation, field notes, and FGDs) as a means of obtaining more information.

3.9.2 Dependability

The researcher gave an external reviewer access to the collected data, and an audit trail was established to allow content experts to judge the dependability of the findings.

3.9.3 Conformability

The researcher was neutral and, therefore, did not entice or influence participants to provide certain answers. The researcher displayed a high degree of professionalism and remained unbiased.

3.9.4 Transferability

To ensure the transferability of the research findings, the researcher conducted a pilot study at Centenary House. The information gathered from the interviews was saved on a disc, and the researcher ensured that only one interview was saved on a disc to guarantee smooth translation and transferability. Finally, trustworthiness was ensured by a thorough and thick description of source data and a fit between the data and the emerging analysis.

3.10 Data management

Data management refers to managing all aspects of the collection, use, and sharing of data. Conducting responsible research is more than avoiding the intentional fabrication or falsification of data. Because data provides the factual basis for scientific work, the value of research depends directly on integrity in and management of all aspects of the collection, use, and sharing of data.

Responsible research begins with accurate design and protocol approval; it involves recordkeeping in a way that ensures accuracy and avoids bias (Fraser & Galinksy 2010). Responsible research also guides criteria for including and excluding data from statistical analyses, ending with reporting and publishing of the findings. The researcher is responsible for protecting the integrity of the research records. This responsibility extends to everyone with a role in this study to ensure the integrity of the data (Patton 2002). The ultimate responsibility belongs to the researcher; however, the importance of data means that this responsibility extends to anyone who assisted in planning the study, collecting the data, and analysing or interpreting the research findings (Fraser & Galinksy 2010).

3.11 Pilot study

A pilot survey to test the reliability and consistency of the instrument was conducted prior to the main data collection. This provided an accurate simulation for the time needed to complete the interviews. The pilot study included (10) SCI patients who resided in Centenary House; these patients

were not included in the main study sample. The findings from the pilot study were used to adjust the final questionnaire according to the input from the pilot survey.

During the pilot study, it was noticeable that the participants were wearied from detailed questions about the organisation giving grants. Post the pilot study, the questions were adjusted to only one question. The question was if the participant receives a grant or not, and it had to be answered by a Yes or No response only.

3.12 Bias

Research bias also referred to as experimenter bias, is a process where the researcher performing the research influences the results to portray a particular outcome (Bryman 2006). Some biases are inevitable, but this research attempted to lessen the impact of these biases and consider them during the statistical analysis. Sampling bias was considered carefully during the selection process of the group for the focus group interviews. The researcher carefully represented the entire community component. This research eliminated procedural bias by avoiding pressuring participants. Participants were free to participate in this research and had the right to discontinue the interviews at any stage without providing any reasons. Bias can arise during the research process; however, this study was piloted with a small group of participants prior to the main study to eliminate bias.

3.13 Ethical considerations

The fundamental ethical principles were considered in this study, namely respect for autonomy, beneficence, non-maleficence, and justice. The following steps were considered to follow these four ethical principles:

3.13.1 Process of seeking permissions

This study received ethical approval from the Ethical Committee of the University of Limpopo's Turfloop Research Ethics Committee (TREC) before the

commencement of the study. Prior to data collection, permission to conduct the study was also gained from the Provincial Health Department in Limpopo.

3.13.2 Principle of non-maleficence

This study was not invasive; therefore, no physical harm was anticipated for those participants who displayed emotional distress. In most cases, where people are asked about their challenges, they are likely to become sad and emotional. The researcher organised a psychologist to be on standby so that whoever is affected could receive counselling.

3.13.3 Principle of respect for autonomy

This principle is also referred to as the principle of human dignity and concerns the obligation to respect the autonomy of other persons, which is to respect the decisions made by other people concerning their lives. The researcher has a negative duty not to interfere with the decisions of competent adults, and a positive duty to empower others for whom we are responsible. The participants signed consent forms before participating in the study. The consent forms included information about the study as well as the research aim and objectives. Participants were free to participate in this research and had the right to discontinue their participation at any stage of the research without providing any reasons.

3.13.4 Principle of beneficence

The researcher had an obligation to maximise the benefits for the individual participants while minimising risk of harm to the individual. The researcher also had an obligation to bring about good in all research actions. The participant benefited from the information given in this study which was transformed in recommendations given to the authorities.

3.13.5 Principle of justice

This research has an obligation not to harm others and treat them equally, fairly, and impartially. The right to patient confidentiality was observed in this study.

3.14 Summary

In this chapter, the methodology used in the study, which includes a combination of qualitative and quantitative approaches to data collection, was outlined. The qualitative data were collected using FGDs, while quantitative data were collected using a developed CIM. The validity, reliability, triangulation for the qualitative aspect of the study, trustworthiness, data management, the pilot study, and ethical considerations were also discussed in this chapter. The results of the quantitative and qualitative analyses are presented in the next chapter.

CHAPTER FOUR

PRESENTATION AND INTERPRETATION OF THE RESULTS – PHASE 1

4.1 Introduction

Chapter 3 outlined the research methodology used to collect the data for this study. In this chapter, the quantitative results followed by the qualitative results of the study will be presented and interpreted. The chapter will conclude with a discussion of the qualitative data results.

4.2 Quantitative data results

4.2.1 Demographic profile of the participants

Thirty-five (35) individuals with an SCI participated in this study, of which more than half (57%) were interviewed in hospital and the remainder (43%) in the disability home in Polokwane (Centenary House). The age of the participants ranged from 25 to 59 years, with the mean and median of 36.1 ± 7.6 and 34 (interquartile range (IQR): 10) years, respectively.

Figure 4.1 demonstrates the age distribution of the respondents with a third (34%) falling within the age group 30 to 34 years and the least was 50+ years.

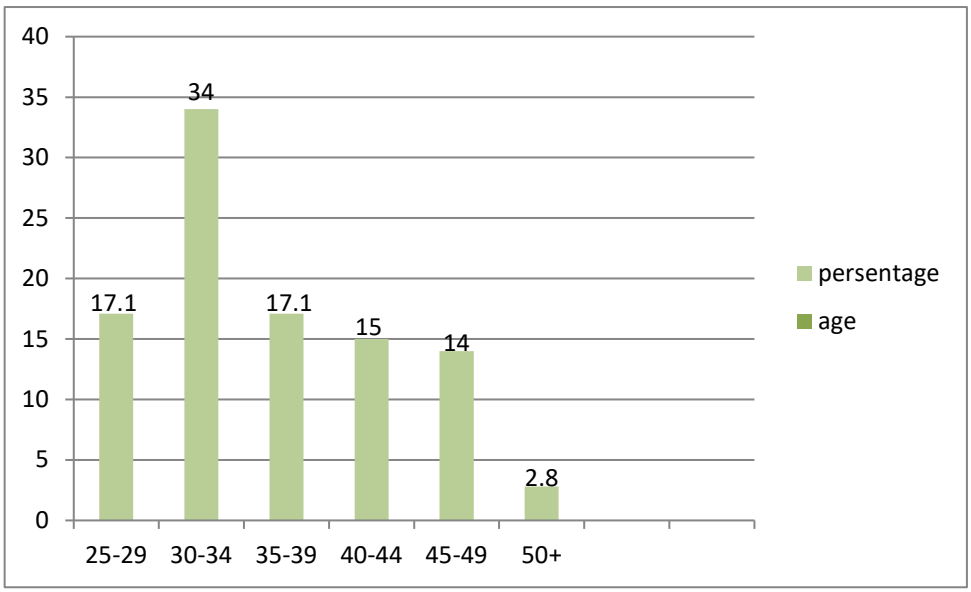

Figure 4.1: Age distribution of respondents (n = 35)

The majority (94%) of the respondents were African, while two (6%) were white. Figure 4.2 shows that most of the participants 21 (60%) were male and 14 (40%) were female.

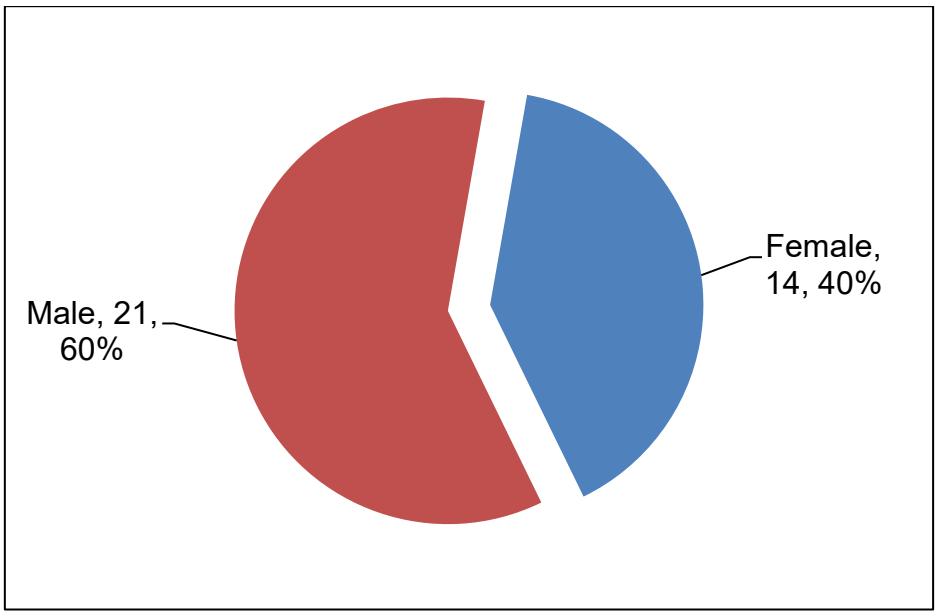

Figure 4.2: Gender distribution of respondents (n = 35)

More than half (55%) had secondary education, 11% had tertiary education, and 34% of the sample's educational level was unspecified. Figure 4.3 shows that close to half (46%) were unemployed and a quarter (26%) were employed; also, 29% of the respondents did not indicate their employment status.

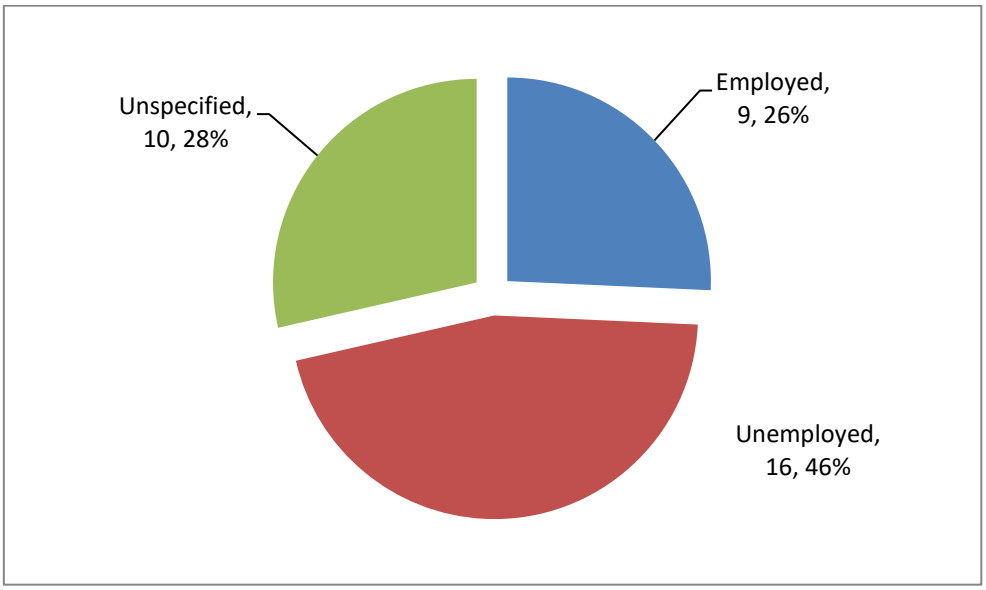

Figure 4.3: Employment status of respondents

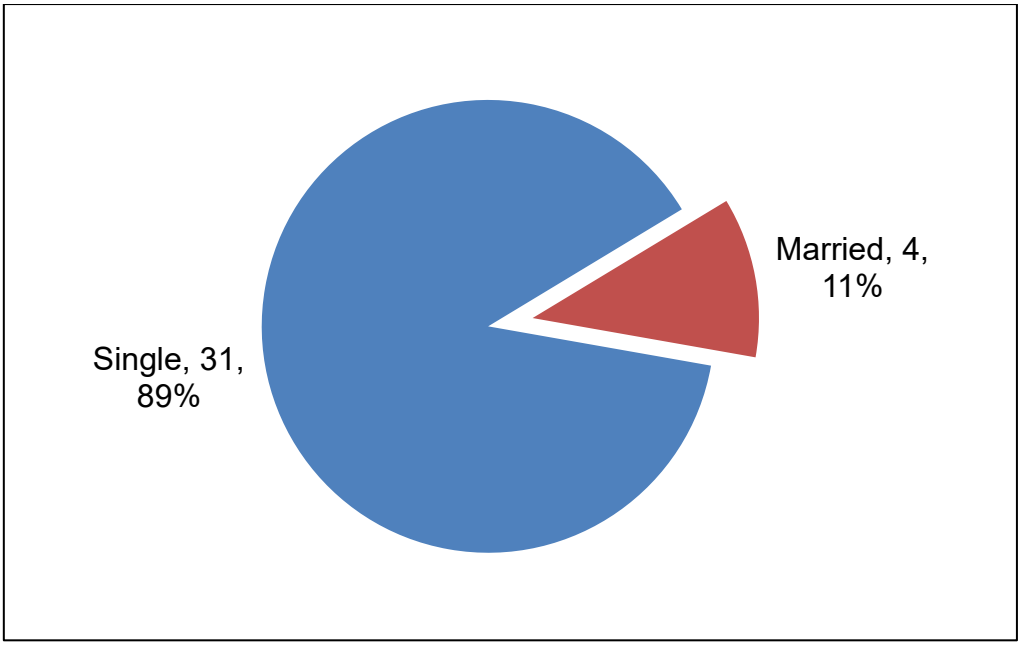

Figure 4.4: Distribution of marital status of respondents (n = 35)

The marital status of the participants is shown in Figure 4.4. The majority of participants, i.e. 31 (89%), were unmarried and 4 (11%) were married. Seventy-one per cent said that they received government grants, while 29% do not receive grants.

Table 4.1: Education, race and grant status of respondents (n = 35)

Variables		**Frequency**	**Percentages**
Education	Secondary	9	26
	Tertiary	16	46
	Unspecified	10	.28
Race	Blacks	32	91.4
	Whites	3	8.6
Receive Grant	Yes	25	71
	No	10	29

4.3 Description of spinal cord injury

Figure 4.5 shows a description of spinal cord injury. The majority (83%) of the participants in this study were paraplegic, followed by both monoplegia and tetraplegia at 8.5%.

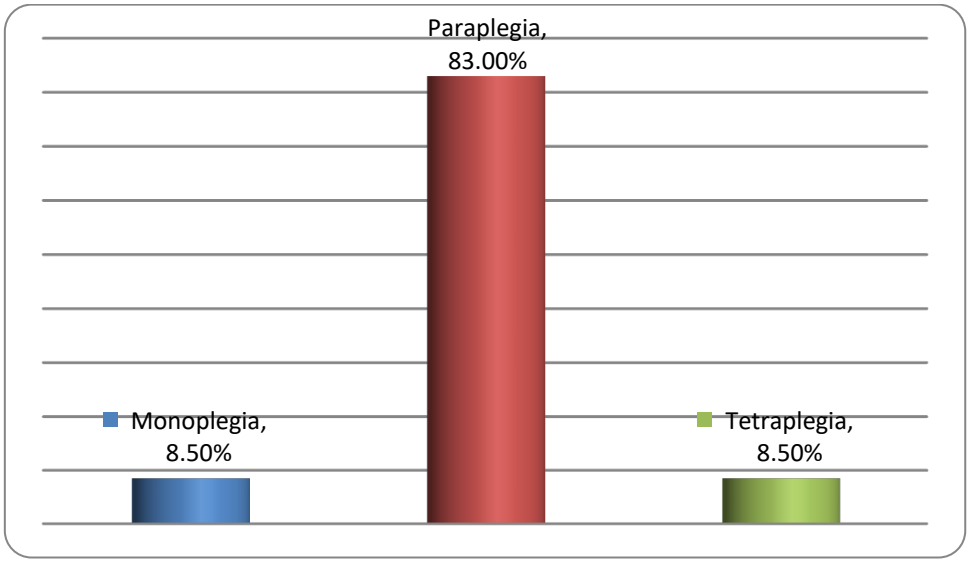

Figure 4.5: Types of injuries of respondents (n = 35)

Figure 4.6 shows that the mean and median number of years since sustaining the injury was 9.9 ±7.8 years (range: 2 to 36 years) and 7 years (IQR: 12 years), respectively.

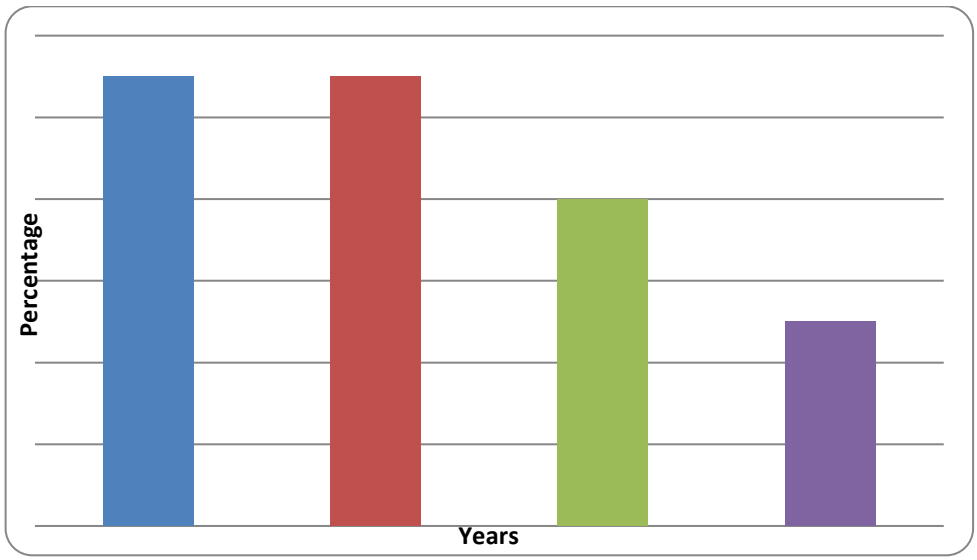

Figure 4.6: Distribution of the number of years injured

4.3.1 Challenges faced by people living with spinal cord injury regarding rehabilitation and integration into the community

Primary data were generated and collected regarding the rehabilitation and community integration challenges of PLWSCI using the SCICRM tool (Maleka 2011; McColl et al 2001), which was discussed at length in Chapter 3. Table 4.2 shows the results of the SCICR tool using Maleka's (2011) four-point scale to judge whether a given a patient with an SCI was successfully reintegrated into the community after his/her injury.

Table 4.2: Results of the SCICR tool

AG	AGG	RAC	GEN	LOC	INJTYPE	B	C	D	E	F	G	H	K	L	SCR	SCR%	RE-INTEGR
39	3	B	F	HOS	Paraplegia	15	12	15	18	15	13	13	15	10	126	95	Full
31	2	B	F	HOS	Paraplegia	15	11	12	17	14	12	13	15	11	120	91	Full
44	4	B	F	HOS	Paraplegia	15	9	9	14	13	14	10	11	6	101	77	Mod
25	1	B	M	HOS	Paraplegia	15	9	11	14	10	10	10	8	5	92	70	Mod
30	1	B	M	HOS	Paraplegia	15	8	9	14	12	15	9	10	9	101	77	Mod
40	3	B	F	HOS	Monoplegia	15	12	15	18	15	15	13	11	4	118	89	Full
34	2	B	M	HOS	Paraplegia	15	10	11	15	14	12	11	8	6	102	77	Mod
40	3	B	M	HOS	Monoplegia	15	12	15	18	15	14	11	11	4	115	87	Full
38	3	B	F	HOS	Monoplegia	15	12	14	18	15	15	13	13	5	120	91	Full
30	1	B	M	HOS	Tetraplegia	4	4	2	12	6	2	4	4	4	42	32	No
46	4	B	M	HOS	Paraplegia	7	4	4	13	10	10	10	10	8	76	58	Min
29	2	B	M	HOS	Paraplegia	10	7	8	14	11	10	10	10	6	86	65	Mod

AG	AGG	RAC	GEN	LOC	INJTYPE	B	C	D	E	F	G	H	K	L	SCR	SCR%	RE-INTEGR
33	2	B	F	HOS	Paraplegia	15	10	11	14	10	15	10	7	6	98	74	Mod
28	1	B	M	HOS	Paraplegia	15	12	12	16	14	12	9	6	6	102	77	Mod
30	1	B	M	HOS	Paraplegia	15	8	10	14	10	10	10	6	3	86	65	Mod
46	4	B	M	HOS	Paraplegia	15	9	12	17	10	9	9	11	5	97	73	Mod
35	2	B	M	HOS	Paraplegia	15	12	11	15	13	9	8	11	2	96	73	Mod
31	2	B	M	HOS	Paraplegia	15	10	6	11	13	14	13	9	7	98	74	Mod
26	2	B	M	HOS	Paraplegia	15	8	10	14	10	10	9	10	8	94	71	Mod
28	2	B	M	HOS	Paraplegia	15	12	11	17	13	15	13	15	9	120	91	Full
39	3	B	F	CEN	Paraplegia	12	12	13	18	15	12	8	15	4	109	83	Full
31	2	B	M	CEN	Paraplegia	6	5	11	18	6	15	3	8	4	76	58	Mod
59	4	W	F	CEN	Paraplegia	15	12	15	18	15	15	9	11	0	110	83	Full
30	1	B	M	CEN	Paraplegia	15	11	15	17	15	15	15	13	9	125	95	Full
31	2	W	F	CEN	Paraplegia	15	11	15	18	15	15	15	12	5	121	92	Full
47	4	B	F	CEN	Paraplegia	14	12	12	18	15	12	8	15	5	111	84	Full
45	4	B	M	CEN	Tetraplegia	12	9	6	18	12	12	3	15	6	93	70	Mod
33	2	B	M	CEN	Paraplegia	9	12	9	18	15	12	5	15	4	99	75	Mod
48	4	W	M	CEN	Paraplegia	13	12	12	18	15	13	9	14	3	109	83	Full
37	3	B	F	CEN	Paraplegia	8	11	10	17	12	13	2	15	4	92	70	Mod
41	3	B	F	CEN	Tetraplegia	6	6	8	15	3	6	6	7	4	61	46	Min

AG	AGG	RAC	GEN	LOC	INJTYPE	B	C	D	E	F	G	H	K	L	SCR	SCR%	RE-INTEGR
28	2	B	M	CEN	Paraplegia	6	12	12	10	5	15	12	8	3	83	63	Mod
33	2	B	F	CEN	Paraplegia	14	7	3	8	12	12	3	15	6	80	61	Mod
38	3	B	F	CEN	Paraplegia	15	11	15	15	14	15	8	12	2	107	81	Full
40	3	B	M	CEN	Paraplegia	14	12	12	15	14	12	8	15	2	104	79	Mod

A= Age *G=Gender* *D= Conformity* *G=Independence*
L=Rehabilitation relationship *G= Age group* *B= Orientation* *E= Close and diffuse*
H= Productivity *KSG= Total* *R=Race*

C=Acceptance *F= Living situation* *K=Leisure* *SCR= Score* *REINTI = Reintegration type* *LOC= Location*

4.3.2 Community reintegration

Table 4.3 shows that 37% of the respondents were fully reintegrated. Moderate reintegration was above average (54.4%), while 5.7% were minimally integrated and 3.9% failed to reintegrate into their communities.

Table 4.3: Percentage of community reintegration

Level of Integration	Frequency	Per Cent (%)
Full Reintegration	13	37
Moderate Reintegration	19	54.4
Minimal Reintegration	2	5.7
No Reintegration	1	3.9
Total	35	100

.

4.3.3 Rehabilitation team's home visit rate

Participants rated home visits by the rehabilitation team to SCI patients as extremely poor. Table 4.4 indicates that two-thirds (66%) of SCI patients rated the rehabilitation team a zero-rating. The rehabilitation teams' home visits were further rated as "never happened" (51%) and one to "rarely happened" (14.3%). This is a clear indication of the need to introduce a suitable rehabilitation programme.

Table 4.4: Rehabilitation team followed SCI patients' health condition until discharged

Scores	Frequency	Percent (%)	Cumulative %
0	18	51.4	51.4
1	5	14.3	65.7
2	8	22.9	88.6
3	4	11.4	100.0
Total	**35**	**100.0**	

Table **4**.*5:* Rehabilitation team followed sci patients' health condition until discharged (levering cross-tabulation)

HOME VISIT SCORE	FULL REINTEGRATION	MINIMAL REINTEGRATION	MODERATE REINTEGRATION	NO REINTEGRATION	TOTAL
NEVER HAPPENS (0)	7	1	9	1	18
RARELY HAPPENS (1)	1	0	4	0	5
SOMETIME HAPPENS (2)	2	1	5	0	8
ALWAYS HAPPENS (3)	3	0	1	0	4
TOTAL	13	2	19	1	35

Table 4.5 shows that 75% of the patients who received a home visit from their rehabilitation team were fully reintegrated into their community. Of those who did not receive any home visits, only 39% managed to fully reintegrate into their communities.

4.3.4 Orientation

Overall, the participants said they are always able to make decisions regarding their life and family needs, remember things told and events easily, able to get up and out of bed in the morning, and able to wash themselves. There was no significant difference between those interviewed in the hospital and in the disability home ($p > 0.05$) as shown in Table 4.6.

Table 4.6: Orientation

	Median Mean	Hospital		Centenary house		P-values
		Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	
make decisions regarding your life and family needs	3 (2.9)	2.8 (0.5)	3 (0)	3 (0)	3 (0)	0.1224
remember things told and events easily	3 (2.9)	2.9 (0.4)	3 (0)	3 (0)	3 (0)	0.1221
able to get up and out of the bed in the morning	3 (2.7)	2.8 (0.5)	3 (0)	2.6 (1.0)	3 (0)	0.9781
able to wash yourself	3 (2.6)	2.7 (0.8)	3 (0)	2.5 (1.1)	3 (0)	0.6659
able to dress yourself	3 (2.7)	2.8 (0.6)	3 (0)	2.7 (0.9)	3 (0)	0.7413

4.3.5 Acceptance and conformity

Regarding acceptance, no statistically significant difference was found between the items of the two groups ($p < 0.05$) as shown in Table 4.7. There was a significant difference between the two groups regarding the ability to care for their livestock, ability to teach children home keeping tasks, satisfaction with their ability to physically assist someone, and feeling that they are a part of their community ($p < 0.05$).

Table 4.7: Acceptance and conformity

	median (mean)	Hospital		Centenary house		p-values
		mean SD)	median (IQR)	mean (SD)	median (IQR)	
acceptance						
I am accepted in this community	3 (2.6)	2.5 (0.8)	3 (1)	2.7 (0.5)	3 (1)	0.4830
Able to attend social events in your community (funerals, parties etc.)	2 (2.3)	2.4 (0.8)	2 (1)	2.1 (0.9)	2 (1)	0.6024
Able to attend community structures meetings or meeting	3 (2.4)	2.4 (0.5)	2 (1)	2.4 (1.0)	3 (1)	0.2924
Satisfied with appearance in the public	2 (2.4)	2.3 (0.9)	2 (1)	2.5 (0.5)	3 (1)	0.4647
Conformity						
Able to care for your livestock	3 (2.3)	2.1 (0.8)	2 (1)	2.7 (0.8)	3 (0)	0.0082
Able to teach children home keeping tasks	3 (2.3)	2.0 (0.9)	2 (0.5)	2.7 (0.8)	3 (0)	0.0012
Able to use the same transport you used before the injury	2 (2.1)	1.9 (0.9)	2 (1.5)	2.3 (0.8)	2 (1)	0.2929
Satisfied with your ability to physically assist someone	2 (2.3)	2.0 (0.7)	2 (1)	2.6 (0.5)	3 (1)	0.0140
I feel like part of this community, like i belong here	2 (2.3)	1.9 (0.9)	2 (0.5)	2.8 (0.4)	3 (0)	0.0011

4.3.6 Close and diffuse relationships and living situation

The mean score regarding close and diffuse relationships is shown in Table 4.8. There was a significant difference between the two groups regarding satisfaction with communication with people around them, with visitors, with help or support that they received from family and friends, and with their ability to solve family and friends' problems ($p < 0.05$). Regarding their living situation, there was a significant difference between the two groups regarding "I like where I'm living now" and "able to get to the clinic and/or hospital" ($p < 0.05$). As can be seen in Table 4.8, there was no statistically significant difference in "able to move around in your home", "able to feed yourself", "able to move around uneven/hill area" and "satisfied in your family and community" ($p > 0.05$).

Table 4.8: Close and diffuse relationships and living situation

	Median (Mean)	Hospital		centenary house		P-values
		Mean (SD)	median (IQR)	mean (SD)	median (IQR)	
Close/diffuse relationships						
Satisfied with interaction with other people	3 (2.4)	2.3 (0.8)	2 (1)	2.7 (0.6)	3 (1)	0.0688
Able to carry out your community role	2 (2.2)	2.7 (0.7)	2 (0)	2.4 (0.9)	3 (1)	0.0553
Satisfied with communication with people around me	3 (2.5)	2.2 (0.7)	2 (1)	2.9 (0.4)	3 (0)	0.0023
Satisfied with visitors	3 (2.5)	2.2 (0.7)	2 (1)	2.9 (0.4)	3 (0)	0.0010
Satisfied with help/support that i receive from family and friends	3 (2.6)	2.5 (0.5)	2 (1)	2.9 (0.4)	3 (0)	0.0128
Satisfied with ability to	3 (2.6)	2.4 (0.6)	2 (1)	2.8 (0.4)	3 (0)	0.0356

	Median (Mean)	Hospital		centenary house		P-values
		Mean (SD)	median (IQR)	mean (SD)	median (IQR)	
solve family and friends' problems						
Living situation						
I like where i'm living now	3 (2.4)	2.3 (0.7)	2 (1)	2.7 (0.6)	3 (0)	0.0243
I can be independent in this community	3 (2.5)	2.4 (0.8)	2.5 (1)	2.5 (1.1)	3 (0)	0.1540
Able to go back to work	3 (2.3)	2.3 (0.8)	2 (1)	2.5 (1.1)	3 (1)	0.1935
Able to attend school or training programmes in community	3 (2.5)	2.5 (0.6)	3 (1)	2.5 (1.1)	3 (0)	0.2478
Able to get to the Clinic/hospital	3 (2.6)	2.5 (0.6)	2.5 (1)	2.9 (0.4)	3 (0)	0.0242

4.3.7 Productivity and independence

No significant association was noted between "able to collect a communal water tap", able to wash dishes, clothes etc.", "able to cook a meal for your family", "able to work in your garden/yard/field" ($p > 0.05$), while "I've something to do in community" indicates a significant difference between the two groups ($p < 0.05$).

Table 4.9: Independence and productivity

	Median (mean)	Hospital		Centenary house		P-values
		Mean (SD)	median (IQR)	mean (SD)	median (iqr)	
independence						
able to move around in your home	3 (2.7)	2.5 (0.8)	3 (1)	2.9 (0.3)	3 (0)	0.0140
able to feed yourself	3 (2.5)	2.3 (0.8)	2 (1)	2.7 (0.8)	3 (0)	0.0224
able to move around in your community	3 (3.3)	3.8 (6.9)	2 (1)	2.7 (0.8)	3 (0)	0.0633
able to move around uneven/hill area	2 (2.2)	2.1 (0.7)	2 (0.5)	2.5 (1.1)	3 (1)	0.0264
satisfied in your family/community	3 (2.5)	2.2 (0.6)	2 (1)	2.8 (0.4)	3 (0)	0.0034
productivity						
i've something to do in community	3 (2.4)	2.2 (0.8)	2 (1)	2.6 (0.8)	3 (1)	0.0423
able to collect a communal water tap	2 (2.1)	2.1 (0.8)	2 (0.5)	2.1 (1.3)	3 (3)	0.3256
able to wash dishes, clothes, etc.	2 (2.2)	2.1 (0.8)	2 (1)	2.3 (1.1)	3 (1)	0.1364
able to cook a meal for your family	2 (2.1)	2.4 (0.5)	2 (1)	1.8 (1.0)	2 (2)	0.0953
able to work in your garden/yard/field	2 (2.1)	2.1 (0.7)	2 (1)	2.1 (0.9)	2 (2)	0.9148

4.3.8 Leisure and rehabilitation

There was no statistically significant association in “there are things that I can do in this community for fun in my free time”, “able to do an activity for self-enjoyment or relaxation”, “able to go shopping in town”, and “able to do any physical activity such as plying any sport” between the two groups ($p > 0.05$). The mean score of participants from the centenary house was significantly higher than the counterpart regarding “able to go out with friends” or “watch a soccer match at a stadium” (Table 4.10).

Table 4.10: Leisure and rehabilitation

	MEDIAN (MEAN)	HOSPITAL		CENTENARY HOUSE		P-VALUES
		MEAN (SD)	MEDIAN (IQR)	MEAN (SD)	MEDIAN (IQR)	
LEISURE						
THERE ARE THINGS THAT I CAN DO IN THIS COMMUNITY FOR FUN IN MY FREE TIME	2(2.2)	2.1 (0.9)	2 (1)	2.3 (0.8)	2 (1)	0.2754
ABLE TO DO AN ACTIVITY FOR SELF-ENJOYMENT OR	2 (2.1)	2.1 (0.9)	2 (1)	2.3 (0.8)	2 (1)	0.4338

	MEDIAN (MEAN)	HOSPITAL		CENTENARY HOUSE		P-VALUES
		MEAN (SD)	MEDIAN (IQR)	MEAN (SD)	MEDIAN (IQR)	
RELAXATION						
ABLE TO GO SHOPPING IN TOWN	2 (2.0)	1.9 (0.7)	2 (0)	2.1 (0.8)	2 (1)	0.3325
ABLE TO GO OUT WITH FRIENDS OR WATCH A SOCCER MATCH AT STADIUM	2 (2.7)	2.8 (4.6)	2 (0.5)	2.5 (0.6)	3 (1)	0.0227
ABLE TO DO ANY PHYSICAL ACTIVITY SUCH AS PLAYING ANY SPORT	2 (1.7)	1.7 (0.9)	2 (1)	1.7 (0.9)	2 (1)	0.8337
REHABILITATION						
REHABILITATION PERIOD WAS ENOUGH TO PROMOTE MY REINTEGRATION INTO THIS COMMUNITY	2 (1.5)	1.9 (0.6)	2 (0.5)	1.1 (0.9)	1 (2)	0.0076
I RECEIVED A HOME VISIT FROM THE REHABILITATION TEAM REGULARLY	1 (1)	1.1 (0.9)	1 (2)	0.9 (0.7)	1 (1)	0.7918
DURING MY ADMISSION AT THE HOSPITAL, ALL MEMBERS OF THE REHABILITATION TEAM VISITED ME	2 (1.5)	1.7 (0.9)	2 (1)	1.2 (0.8)	1 (1)	0.0590
DURING MY ADMISSION AT THE HOSPITAL, ALL THE REHABILITATION TEAM MEMBERS WERE FOLLOWING	1 (0.9)	1.5 (0.9)	1.5 (1)	0.1 (0.4)	0 (0)	<0.0001

	MEDIAN (MEAN)	HOSPITAL		CENTENARY HOUSE		P-VALUES
		MEAN (SD)	MEDIAN (IQR)	MEAN (SD)	MEDIAN (IQR)	
MY CONDITION UNTIL DISCHARGE						

4.4 Qualitative data analysis

The qualitative results presented in this study emerged from data analysis using Tesch's open coding method following eight steps described by Creswell (2008). These steps outline how the data were analysed.

4.4.1 Step 1: Reading the data

The researcher got a sense of the whole by reading all the verbatim transcriptions carefully, which produced ideas about the data segments and how they look or what they mean. The meanings that emerged during reading were written down, as well as all ideas as they came to mind. The researcher carefully and repeatedly read the transcripts of all the participants and understood them. An uninterrupted period to digest and think about the data in totality was created. The researcher engaged in data analysis and wrote notes and impressions as they came to mind.

4.4.2 Step 2: Reduction of the collected data

The researcher scaled down the collected data to codes based on the existence or frequency of concepts used in the verbatim transcriptions. The researcher then listed all the topics that emerged during the process of scaling down. The researcher grouped similar topics together, and those that did not have associations were clustered separately. Notes were written in the margins, and the researcher started recording thoughts about the data in the margins of the paper where the verbatim transcripts appeared.

4.4.3 Step 3: Asking questions about the meaning of the collected data

The researcher read the transcriptions again and analysed them. This time, the researcher asked herself questions about the transcriptions of the interviews based on the codes (mental picture codes when reading), which existed from the frequency of the concepts. The following questions emerged: “Which words describe it?” “What is this about?” “What is the underlying meaning?”

4.4.4 Step 4: Abbreviation of topics to codes

The researcher started to abbreviate the topics that emerged as codes. These codes needed to be written next to the appropriate segments of the transcription. Differentiation of the codes by including all meaningful instances of a specific code’s data were made. All these codes were written in the

margins of the paper against the data they represented in a different colour than the one in step 3.

4.4.5 Step 5: Development of themes and sub-themes

The researcher developed themes and sub-themes from the coded data and the associated texts and reduced the total list by grouping topics that relate to one another to create meaning of the themes and sub-themes.

4.4.6 Step 6: Compare codes, topics, and themes for duplication

The researcher reworked from the beginning to check the work for duplication and to refine the codes, topics, and themes where necessary. Using the list of codes, she checked for duplication. The researcher grouped similar codes and re-coded others where necessary so that they fit in the description.

4.4.7 Step 7: Initial grouping of all themes and sub-themes

The data belonging to each theme were assembled in one column, and preliminary analysis was performed, which was followed by the meeting between the researcher and co-coder to reach consensus on themes and sub-themes that each one has produced independently.

4.4.8 Step 8: Re-coding if necessary

A necessity to re-code emerged as some of the themes that were reached independently were merged. Saturation of data was achieved related to the major themes and all sub-themes, which is confirmed through the identification of more verbatim quotes or excerpts from the transcription used in the data analysis, as well as five themes and five sub-themes that emerged, except for the sub-themes of theme four.

4.5 Saturation of data

Saturation was achieved related to the major themes and all sub-themes that were confirmed through the identification of more verbatim quotes or excerpts from the transcription used in the data analysis, as well as six themes and five more sub-themes that emerged, except for the sub-themes of theme four.

Table 4.11: Themes and sub-themes reflecting the challenges faced by healthcare professionals dealing with the rehabilitation of SCI patients in the Limpopo Province, South Africa

Main themes	Sub-themes
Challenges experienced by healthcare professionals caring for patients with SCIs	Caring for SCI patients were viewed as a difficult role that poses problems at multiple levels of care Lack of material and human resources is problematic during the provision of care to patients Lack of adherence to treatment protocols for the management of patients with SCIs Existing lack of skills and shortage of healthcare professionals to care for patients outlined as a challenge at multiple levels Existing hospital policies a challenge towards proper management and access of care to patients Lack of training and dialogue programmes for healthcare professionals pose difficulty for enhancement of care skills Lack versus existence of an outreach programme, call system, outpatient care, and home visits problematic Lack of communication among professionals a hindrance towards provision of quality care

Main themes	Sub-themes
Healthcare practices for caring for SCI patients by healthcare professionals	Lack of rehabilitation programme resulted from non-performance of operations in the context of the study Existence of limited rehabilitation activities appreciated and encouraged Existence of daily care for the patients by specific healthcare professionals organised by the team Various roles played by healthcare professionals The importance of existing multidisciplinary team meetings; meetings with patients and families Existing booking systems at multiple levels for patients Existing precautions taken during provision of care
Experiences of healthcare professionals related to caring for patients with SCIs	Tales of experiences related to the absence of a rehabilitation programme for spinal cord in SCI injury patients Provision of care not limited to SCI patients only Appreciation of each other skills, as healthcare professionals and integration of care Existing referral systems for patients to different healthcare professionals and facilities Explanation of treatment, management, and care for SCI patients that focus on the acute period
Complications resulting from lack of rehabilitation programmes for SCI patients	Patients' physical and psychological impairments resulting from lack of rehabilitation programmes Patients' exposure to complications due to lack of rehabilitation programmes Lack of healthcare professionals' skills outlined as risk resulting in patients' complications
Suggestions related to aspects that	Significance to outline a specific period to start with rehabilitation of SCI patients

Main themes	Sub-themes
might lead to the provision of quality care to patients with SCIs	The importance of additional human and enough material resources was outlined Importance of full assessment of the patients by different healthcare professionals explained A need for training courses for management, treatment, and care for patients with SCIs A need for a special unit with specialist and community rehabilitation centres emphasised The importance of home visits
Experiences of patients with SCI patients as observed by healthcare professionals	Existence of self-stigmatisation portrayed by patients Existing changes at various levels of patients' life observed A need for regaining importance for life desired by patients Challenges experienced by patients at various levels of life observed

4.6 Qualitative data results discussion

The findings are based on six themes and their sub-themes that emerged during data analysis using Tesch's open coding qualitative data analysis method as described by Creswell (2008). The findings are supported by direct participants' excerpts and existing literature.

Table 4.12: Challenges experienced by healthcare professionals

Theme	Sub-themes
Challenges experienced by healthcare professionals caring for patients with SCIs	Caring for SCI patients viewed as a difficult role that poses problems at multiple levels of care

	Lack of material and human resources problematic during provision of care to patients Lack of adherence to treatment protocols for management of patients with SCIs Existing lack of skills and shortage of healthcare professionals to care for patients outlined as a challenge at multiple levels Existing hospital policies a challenge towards proper management and access to care Lack of training and dialogue programmes for healthcare professionals pose a challenge to the enhancement of care skills Lack versus existence of outreach programmes, call system, outpatient care, and home visits problematic Lack of communication among professionals a hindrance towards provision of quality care

4.6.1 Theme 1: Challenges experienced by healthcare professionals caring for patients with spinal cord injuries

The findings of the qualitative data revealed that the participants had mixed challenges regarding caring for patients with SCIs and they concluded that a lack of material and lack of human resources are the main challenges during the rehabilitation process of SCI patients in the Limpopo Province. The discussion about the challenges experienced by the healthcare professionals caring for patients with SCI is reflected in the following sub-themes.

- Sub-theme 1.1: Caring for spinal cord injury patients viewed as a difficult role that poses problems at multiple levels of care

The findings revealed that the rehabilitation team and the healthcare professionals in Limpopo are facing mixed challenges in treating and rehabilitating SCI patients. Some professionals verbalised that they are the only rehabilitation team in Limpopo and specifically Polokwane (Pietersburg hospital). This situation created extra challenges and a more strenuous work environment. Participants were still providing positive feedback about the possibility of producing acceptable rehabilitation outcomes for the PLWSCI in the Limpopo Province because they are still working as one team.

The difficult roles that professionals play and pose problems at multiple levels of care were outlined by one physiotherapist:

"In this hospital, we don't surgically operate spinal cord injury patients that is why we don't have a proper rehabilitation programme for the spinal cord injuries patients. Also, the hospital didn't manage the programme of the rehabilitation according to the protocol supposed to be, for instance we start the rehabilitation for the spinal cord injury patients after six weeks while according to the programme which is known to all the practitioners we [are] supposed to start within three days after the operation day and we [are] supposed to start by the procedure of the chest physiotherapy and static exercise as physiotherapist while other practitioners must also start [as] early as the dietician, psychologist and so on."

An occupational therapist supported the statement of the physiotherapist:

"Yes, this usually leads to muscle wasting and in some cases bedsores and so on and would be difficult for the team when the patient is in this state to assist them to return back to normal functioning."

The findings of this study support the findings of the study conducted by Burns and O'Connell (2012) on the challenges of SCI care in the developing world by indicating that the significant advances in SCI rehabilitation have not affected

the majority of persons affected by SCI. Additionally, it was stated that those living in low resourced or developing regions of the world did not benefit from these advances.

- Sub-theme 1.2: Lack of material and human resources problematic during provision of care to patients

Healthcare practitioners and the rehabilitation team mentioned the lack of material and human resources as problematic during the provision of care to patients. Practitioners identified bracing, wheelchairs, commodes, and crutches as the main challenged resources when it comes to the rehabilitation of SCI patients. This was confirmed by one of the occupational therapists:

"I think one of our biggest challenges is lack of resources like of bracing, wheelchairs, commodes, and sometimes crutches as they sometimes are delayed from the suppliers."

A physiotherapist added: "*Actually, I want to add to my colleague that also repairing of the equipment sometimes are affecting the mobility of the patient and as well affecting their community integration in[a]later stage."*

These statements support the study conducted by Weerts and Wyndaele (2011), which found that equipment for PLWSCI needs to be practical, durable, and repairable. It would be ideal if the patient or his/her family could repair their equipment. In case the patient or his/her family were not able to repair the equipment, they should have access to someone who can assist them in repairing the equipment. The availability of equipment and mobility devices for SCI patients will contribute to their successful integration into the community.

- Sub-theme 1.3: Lack of adherence to treatment protocols for management of patients with spinal cord injuries

The findings revealed that one of the weaknesses of the rehabilitation process in Limpopo is the lack of adherence to the treatment protocol for the management of patients with SCIs. Absence of a separated or special ward or

department for SCIs in the Limpopo Province is the main cause of health professionals' absence of treatment protocol adherence.

A rehabilitation doctor who is part of the rehabilitation team in Limpopo said:

"First of all, I would like to mention a very important point that we don't have [a] spinal cord unit here in this hospital, so we don't have rehabilitation specifically for the spinal cord injury patients. This team is [a] rehabilitation team for all orthopaedic cases, including spinal cord injury patients; therefore, it is difficult [for] the team to adhere to the existing protocols for spinal injuries only. The spinal cord injury patient [is] usually admitted at ward N and ward O (the orthopaedic wards) – that is why they were able to receive our service even though it is difficult to adhere to protocols as I have stated."

Another participant with the same view opined:

"This is a tertiary hospital and the complex (Pietersburg and Mankweng) are the only referrals hospital. We still receive referrals from other hospitals in Limpopo regardless if we are operating on these patients or not. So, all other hospitals in Limpopo who got spinal cord injuries patients, they send them here. So, we can't wash our hands and say we don't operate, so we don't do anything. We are trying to help those patients as much as we can. So, we as [the] rehabilitation team, we try to help those patients to the limit we can but total adherence to protocols with the conditions I have stated, it is difficult."

Another participant added:

"As patients admitted in our hospital, they fall under our supervision whether they have fractures or subluxation or dislocation or injury to the spinal cord regardless of the type of the injury or the location of the injury whether in the thoracic or cervical or lumbar spine, still they fall under our supervision and care. The variation of the type of injuries may be the cause of why we don't have[a]specific programme for spinal cord injuries which is problematic at this stage."

The nurses complained about the SCI patients. The core of the complaint is that they do not know under which criterion SCI patients fall and that such patients should have their own unit.

"We need to have a separated spinal unit so that we can adhere to the protocol that guides the care of such patients. It should be separated from the orthopaedic unit. Really, there are a lot of complications of those patients starting from the bedsores, prolonged urine catheter, kidney problems, sudden rise of temperature, chest complications, and other problems which need consultation from other doctors and other specialisation interference."

Adherence to the treatment protocol and the presence of guidelines are the core and the basic management of patients in the medical field. Sackett, Straus, Richardson, Rosenberg and Haynes (2000) delineate two distinct components of guidelines for clinical practice: the summary of the evidence upon which the guidelines are based, and the detailed instructions or recommendations for applying that evidence to our patients.

- Sub-theme 1.4: Existing lack of skills and shortage of healthcare professionals to care for patients outlined as a challenge at multiple levels

Most of the participants in this study mentioned lack of skills and healthcare professionals as the major challenges to care for patients with SCIs because these patients need specialised skills and relevant material resources.

One of the nurses said:

"The management must at least increase the number of the enrolled nurses and professional nurses in [the] orthopaedic ward, at least if they are not able to create [a] special ward or unit for the spinal cord injury. The doctors must give more time in their round for thorough assessment to early discovery of the complications of the spinal cord injury patients instead of leaving this role to the professional nurses to discover the problem and 'til the doctor who will only write or fill a consultation form to other specialist."

Another professional nurse concurred: *"… (mmm) … now we have orthopaedic doctors to manage the spinal cord injury patients although they don't have enough experience to manage those patients".*

Other participants emphasised the fact that the protocol or the programme is available, but the implementation is difficult because of the shortage of professionals. A doctor commented:

"According to our programme here in this hospital, the patient [is] admitted from casualty to the ward. The doctor writes the prescription, and the nurses and sister must follow up. We as [a] team [are] expected to start our work from the first day but unfortunately in this hospital if the patient has [a] spinal cord injury he or she should stay in bed rest for six weeks before we can start; this shows incompetence at a level of the hospital. This is why some of our colleagues complain of delay of their interference with the patient, but this is the protocol. Unless if there is [an] urgent need for early interference, an example chest physiotherapy with special and gentle care …"

The rehabilitation approach must start as early as possible by at least forming the baseline for the treatment of the patient. Nas et al (2015) state that SCI leads to serious disability and complications. The treatment and rehabilitation process of SCI is long, expensive, and requires a multidisciplinary approach. Early rehabilitation is important to prevent disability and complications (Emerich et al 2012).

- Sub-theme 1.5: Existing hospital policies a challenge towards proper management and access of care to patients

Policies are formulated in institutions so that they can guide performance, but the findings revealed that the existing policies do not guide how the SCIs can be managed, and the accessibility of the care by the patients have not been spelt out. This point of view was verified in the following excerpt from a participant: "*In this hospital, we don't operate spinal cord injury patients, that is why we don't have [a] proper rehabilitation programme for the spinal cord injuries patients*".

Another participant supported this opinion:

"Also, the orthopaedic doctors they just come during their round and while they are taking rounds they write their notes (continue treatment) and they go; they don't know the impact that falls on the nurses who work for 12 hours because they need protocols that could guide them in taking care of these patients."

The findings of this study showed a lack of proper management which affects the rehabilitation of the SCI patient. Hospital protocol and policies are the key to the successful treatment of patients (Nas et al 2015).

- Sub-theme 1.6: Lack of training and dialogue programmes for healthcare professionals pose difficulty for the enhancement of care skills

The findings of this study showed a lack of regular courses and updates for the healthcare professionals who care for patients with SCIs. The healthcare professionals did not attend a workshop for the last two years due to the financial situation in the province. An occupational therapist said: *"… (mmm) let me tell you something. The only time we received a workshop here on rehabilitation was in 2014. After that, we never received or held any workshop in this hospital.*"

Another occupational therapist opined:

"Ya … in our school we do have [a] course of spinal cord injuries but is not enough for us to deal with the huge number and cases we are seeing here in this hospital. We have seen only one or two cases at university level but [those] were not enough. Here we come to an area where you can get more experience but still, we need to get more training or some experience to quid us in this dilemma. I think lack of experience does affect us negatively."

A dietician said:

"The facilitator for the last workshop (aaa) … they didn't receive their money while the province under administration, when we ask again for any workshop,

they refused and asked us to pay upfront. Actually, yes. We need extra skills to meet our challenges in this situation."

A team leader (doctor) said: "… *(Silent for moment) … so really for a successful integration to the community we need to do a successful rehabilitation which need more and extra skills in this regard.*"

House, Russell, Kelly, Gerson and Vogel (2009) studied the importance of continuous training for professionals to improve their competency level. They found that professional training in rehabilitation has traditionally focused on the biomedical aspects; therefore, many rehabilitation professionals lack expertise in managing the psychological conditions that are extremely common in SCIs (House et al 2009).

In this sense, empathy is a core skill when communicating and interacting with patients. Empathy has been defined as the ability to understand patients' feelings and concerns, and it has been related to an increased likelihood of patients' adherence to treatment (House et al 2009). Communication skills are emphasised as core competencies for new residents in physical medicine and rehabilitation (Nas et al., 2015). Workshops and regular training improve the skills level of the practitioners (Emerich et al 2012).

- Sub-theme 1.7: Lack versus existence of outreach programmes, call systems, outpatient care, and home visits are problematic

This study revealed that healthcare professionals who deal with SCIs do not have outreach programmes to visit the patients at their homes. The healthcare professionals did not attend a workshop for the last two years due to the financial situation in the province. An Occupational therapist said: "… *(mmm) let me tell you something. The only time we received a workshop here on rehabilitation was in 2014. After that, we never received or held any workshop in this hospital*."

A dietician said:

"The facilitator for the last workshop (aaa) … they didn't receive their money while the province under administration, when we ask again for any workshop, they refused and asked us to pay upfront. Actually, yes. We need extra skills to meet our challenges in this situation."

A team leader (doctor) said: *"… (Silent for moment) … so really for a successful integration to the community we need to do a successful rehabilitation which need more and extra skills in this regard".*

A social worker added:

"Before two, three years … there were two rehabilitation teams for the spinal cord injuries or orthopaedic cases in general (one is here and the other in Mankweng). In 2014, they decided to close the one in Mankweng. That is why now those patients has only chance to meet all the team here in Polokwane."

To develop and maintain the necessary skills to manage PLWSCI, training programmes and workshops should regularly be held for the multidisciplinary team members. The programme should also have experience with SCI patients with different degrees of injury (*Consumer guidelines for SCI rehabilitation* 2016).

- Sub-theme 1.8: Lack of communication among professionals a hindrance towards provision

The study revealed that the professionals experienced challenges regarding communication between them. A Road Accident Fund (RAF) representative said:

"Professionals in the provincial hospital and other district hospital need to have a better communication method between them, in order to help the patients to be referred to the nearest hospitals when they need. Some of those patients may not be able to come every month for rehabilitation here in Polokwane. Some of them are coming from so far, so they need to continue with the nearest hospital for their rehabilitation. I am saying this because transfer of the skills were also needed for our colleagues who are working in other hospitals in order

to help those patients after discharge from the tertiary hospital here in Polokwane."

One of the occupational therapists said:

"Sometimes we make [a] phone call to ask about our patients, and sometimes we call the hospital if they know the patient was still at the regional or any other hospital and we give our advice. Not only us as occupational therapists, also other professionals like physiotherapists they also do the same. The problem is the patients sometimes get discharged without consulting or informing us as professionals about if this patient is ready for discharge or not. The doctors when they decide to discharge the patients, they don't arrange with us the discharge date. You can just come the following day and find the patient was discharged. Fortunately, most of those patients know us and some of them have our numbers, so they call us and try to arrange with us for the follow-up at the monthly clinic or individually at the department. We usually arrange to see them as outpatients or give them later to [the] nearest hospital to see them also as an outpatient. All of these affect patients' care".

The importance of teamwork in SCI care cannot be overemphasised. It is not an easy task to determine the strength and cohesiveness, the experience, and skill level of team members. One, therefore, should understand whether the team members work together every day and communicate properly to promote the care of patients (*Consumer guidelines for SCI rehabilitation* 2016).

4.6.2 Theme 2: Healthcare practice caring for SCI patients by healthcare professionals

The professionals highlighted the positive part of the rehabilitation process and good practice while doing their jobs. It is important to rehabilitate SCI patients so that they can be successfully integrated into the community. The healthcare professionals indicated that it was possible to deliver the rehabilitation service to the SCI patients as much as they can work as a multidisciplinary team. The following seven sub-themes emerged under this theme:

- Sub-theme 2.1: Lack of rehabilitation programme resulted in non-performance of operations in the context of the study

A rehabilitation team in Limpopo only existed at the Pietersburg (Polokwane) hospital. The professionals indicated that the patients needed to be transferred to Gauteng to undergo operations. This situation reduced the functions of the rehabilitation team in Polokwane. A physiotherapist said:

"In this hospital, we don't operate spinal cord injury patients, that is why we don't have [a] proper rehabilitation programme for the spinal cord injuries patients. Also, the hospital don't manage the programme of the rehabilitation according to the protocol."

A doctor added:

"In this hospital, we don't operate spinal cord injuries; we used to send them to George Mukhari Hospital (Medunsa). We can't comment on that (operating spinal patients) because we are not the human resources and we are not management of the hospital who are supposed to supply enough human resources to cater for rehabilitation."

This finding demonstrates the gap in the management of SCI patients in the Limpopo Province, and it shows the absence of special rehabilitation centres in the province. This finding concurs with the finding of Burns and O'Connell (2012) who mentioned the disparities between the developing and developed countries' capacity to deliver rehabilitation services to PLWSCI.

- Sub-theme 2.2: Existence of limited rehabilitation activities appreciated and encouraged

This study found the existence of limited rehabilitation activities are appreciated and encouraged. Doctors and other employees who participated in this study showed an appreciation for the services provided by the rehabilitation team in the province, even though it was limited.

One of the participants said:

"*We still receive referrals from other hospitals in Limpopo regardless of that we are operating on these patients or not. So, all other hospitals in Limpopo who got spinal cord injuries patients, they send them here. So, we can't wash our hands and say we don't operate, so we don't do anything. We are trying to help those patients as much as we can. So, we as rehabilitation team we try to help those patients."*

A physiotherapist stated:

"As patients admitted in our hospital, they fall under our supervision whether they have fractures or subluxation or dislocation or injury to the spinal cord regardless of the type of the injury or the location of the injury whether in the thoracic or cervical or lumbar spine, still they fall under our supervision and care. The variation of the type of injuries may be the cause of why we don't have [a] specific programme for spinal cord injuries which is problematic at this stage. Besides the increase [in] the number of patients, with variety of orthopaedic and neurological conditions together. All of this [has an] impact on [the] limitation of rehabilitation to the spinal cord injury patients."

Regardless of the outcome and limited rehabilitation activities, the doctors and nurses appreciate and encourage the service. A doctor who works as a team leader said*:*

"(hmmm) … Let me tell you something … I have been in this rehabilitation service for more than four years; also, I have been at other hospitals in Pretoria. I can ensure you this team is very excellent in their work of rehabilitating the patients; the only difference is that the patients in Pretoria operated on time, so rehabilitation is starting earlier than here, and the patients are also discharged earlier."

A physiotherapist said: *"During six weeks of rehabilitation, we also arrange for family meetings, and we train the caregiver to take care of the patient after discharge. All of this must be considered as part of rehabilitation"*.

According to Emerich et al (2012), other services offer specialised information and care relative to the needs of the person with an SCI and contribute to a comprehensive medical and therapeutic programme. The facilitation of family meetings should improve the family support, and training of the caregiver should lead to a comprehensive and successful rehabilitation of the SCI patient.

- Sub-theme 2.3: Existence of daily care for the patients by specific healthcare professionals organised by the team

The findings of this study revealed that the professionals do their level best to provide care to these patients. Professionals in the multidisciplinary rehabilitation team confirmed the existence of daily care for the patients by specific healthcare professionals organised by the team. The rehabilitation team leader said:

"According to our programme here in this hospital, the patient [is] admitted from casualty to the ward. The doctor writes the prescription, and the nurses and sister must follow up. We as [a] team [are] expected to start our work from the first day but unfortunately in this hospital if the patient has [a] spinal cord injury he or she should stay in bed rest for six weeks before we can start; this shows incompetence at a level of the hospital. This is why some of our colleagues complain of delay of their interference with the patient, but this is the protocol. Unless if there is [an] urgent need for early interference, as example chest physiotherapy with special and gentle care, like no turning over of the patient and so on."

"Every healthcare organisation is confronted with its inherent problems on a daily basis" (Muller 1996). The management of these problems requires a purposeful group effort, which could be reactive with the application of crisis management routinely, or a formalised quality improvement system could be in operation to minimise these problems and to enable the delivery of quality care. For instance, well-trained professionals should implement a clear rehabilitation programme to facilitate successful rehabilitation and better community reintegration for PLWSCI.

- Sub-theme 2.4: Various roles played by healthcare professionals

Healthcare professionals who participated in this study outlined the various roles they play. One of the professionals who participated in the study said:

"… (mmmm) … of course we suppose all of us to meet the patient and introduce our self and our roles. As the physiotherapists can start with light physiotherapy and psychologist starts with motivating the patient also social worker must help here as most of those people have family that depend on them and others are not working they need the social workers. Also, Road Accident Fund must start off taking their responsibility. Also, [the] dietician must start by prescribing [a] special diet to those patients."

One of the characteristics of professionalism is the pursuit of excellence and the desire to regulate one's performance. The professional health practitioner is personally professionally-ethically accountable for his/her practice (acts and omissions). Practitioners, therefore, are eager to become formally involved in quality assurance or improvement (WHO 2010). Certainly, in South Africa, the activities of healthcare professionals were rarely questioned; however, the public has become increasingly informed about what constitutes good, as well as poor healthcare (Muller 1996).

A person with an SCI must have access to competent SCI rehabilitation care (Emerich et al 2012). Emerich et al.'s (2012) statement require professionals to play various roles. This process commences with the employees in acute care settings that should recommend when the patient will be ready to receive competent and complete rehabilitation care. Physiotherapists and occupational therapists should be able to achieve the best possible health and functional outcomes. Dieticians should compile a suitable diet programme for the patient, and the psychologist and social worker must give the patient the stability and support he/she requires. The family members have the task of supporting and following the healthcare professionals' instructions.

The skills and experience of the team members and their ability to work together should help to deliver the crucial components of a programme that

offers competent care. With their collective expertise, individual members of the team are capable of adapting the rehabilitation process to the unique needs of each patient and family. Even in this situation of shortened inpatient rehabilitation stays and limited access to the best programmes, patients with SCIs can reach their optimal potential and lead productive lives in the community if they have access to an experienced team of healthcare professionals.

- Sub-theme 2.5: The importance of existing multidisciplinary team meetings and meetings with patients and families

The healthcare professionals who participated in this study outlined the importance of existing multidisciplinary team meetings. Moreover, they outlined the importance of meetings with patients and families.

One of the professionals said:

"Usually we meet here every Thursday. Giving feedback in how far we are on managing those patients. Everyone here comes with a feedback whatever is his discipline. By six weeks this is where our patient starts coming out of bed, here the orthotists start their work on the patient who needs callipers or [a] wheelchair or braces. This is the point where the patient starts being independent. As well, this is the step forward to discharge the patient from the hospital."

- Sub-theme 2.6: Existing booking systems at multiple levels for patients

The finding of this study outlined the existence of alternative methods created by the professionals to fill the gap and assist the patient with successful community integration by booking them extra rehabilitation sessions after discharge from the hospital. An orthotist said in this regard:

"…(aaa)… (silent for moment) about alternative methods of rehabilitating the spinal cord injury patients, still they can book themselves to see any of our professionals individually through our department which also is difficult to make it more than once a month."

Another occupational therapist said:

"We usually arrange to see them as outpatients or give them later to [the] nearest hospital to see them also as an outpatient." A dietician added: *"We as a team used to book so that we can meet the spinal cord injuries patients every third week of the month here in this hospital at the OT boardroom. All the disabled people who come for that session on the third week of the month they were discharged from this hospital."*

- Sub-theme 2.7: Existing precautions taken during provision of care

The findings of this study showed that the practitioners take precautions during the provision of patients' care. One doctor said:

"As I told you earlier, this team only deals with the trauma conditions as they can be admitted in the orthopaedic wards, while the pathological conditions [are] admitted to the medical ward. About the precautions, they do take precautions when they deal, for example when they have [a] spinal TB case, they wear the mask and gloves and gowns."

A physiotherapist said:

"Taking precautions … Yes, we protect our self by using[a]mask and wearing aprons and gloves, but the hospital does not give prophylaxis medicine to protect us. We [are] supposed to take some tablets as prophylaxes when we deal with such patients but actually this is not the case here in Polokwane hospital at least."

4.6.3 Theme 3: Experiences of healthcare professionals related to caring for patients with spinal cord injuries

The practising phase of the rehabilitation team requires that professionals apply their knowledge, skills, and experience to care for patients with SCIs. They need to apply their experience to determine what care to provide and how to care for their patients (Young, Van Niekerk & Mogotlane 2006). Professionals

revealed their experiences related to caring for patients with SCIs. The following sub-themes emerged from this theme:

- Sub-theme 3.1: Tales of experiences related to the absence of a rehabilitation programme for spinal cord injury patients

This study found that professionals were experiencing challenges due to the absence of a rehabilitation programme in the province. The rehabilitation programme was absent because there was no spinal unit for the SCI patients in all of Limpopo; therefore, the patients needed to be transferred to Gauteng to receive operations.

A team leader said:

"First of all, I would like to mention a very important point that we don't have spinal cord unit here in this hospital, so we don't have rehabilitation specifically for the spinal cord injury patients. This team is[a]rehabilitation team for all orthopaedic cases, including spinal cord injury patients. The spinal cord injury patient usually admitted at ward N and ward O (the orthopaedic wards) that is why they were able to receive our service. This group found the head of orthopaedic department to help his patients. In this hospital, we don't operate spinal cord injuries; we used to send them to George Mukhari Hospital (Medunsa). We can't comment on that (operating spinal patients) because we are not the human resources and we are not management of the hospital..."

Regardless of the obstacles, the healthcare professionals are still caring for those patients:

"I have been in this rehabilitation service for more than four years. Also, I have been at other hospitals in Pretoria. I can assure you this team are very excellent in their work; the only difference is that the patients in Pretoria [are] operated very soon, so rehabilitation is starting earlier than here, and the patient is also discharged earlier."

It is evident from the participants' statements that a standard rehabilitation programme was absent. Standards should be developed that clearly and

objectively define the way in which clinical services and their supporting systems are rendered and managed (Muller 1996). A standard is measuring and evaluating actual performance or service delivery (Burns & O'Connell 2012). There are three types of standards, namely structure, process, and outcome standards (Donabedian, 2005; McDonald, Sundaram, Bravata, Lewis, Lin, Kraft, McKinnon, Paguntalan & Owens 2007). The absence of the structure standard (or spinal unit in this case) caused challenges in all other processes of a standard rehabilitation programme (McDonald et al 2007).

- Sub-theme 3.2: Provision of care not limited to spinal cord injury patients only

During the interviews, professionals mentioned that their provision of care was not limited to spinal cord injury patients, but that they extend their services to other patients who need their services. This experience was supported by the following excerpt from a participant:

"As I told you earlier, this team only deal with the trauma conditions as they can be admitted in the orthopaedic wards, while the pathological conditions [are] admitted to the medical ward. I can't say they didn't receive any rehabilitation; they do receive individual care from different disciplines individually but not from us as a team. Like we have other colleagues who work in [the] medical ward. They take care of these cases individually according to the need of patient."

Another participant also indicated:

"All in-hospital patients receive services from all disciplines individually. Like each professional gives his service regardless of other professionals' programmes. Some allied services in other wards (not the orthopaedic ward), they work with [a] referral system like they see the patient if the patients are referred to them; otherwise, patients will be referred to their origin or nearest hospital to receive the service."

In South Africa, it is assumed that quality in healthcare can be based on the quality of professional training and education including ethical, legal, and

professionalism (Muller 1996). The standard of healthcare practice in South Africa has been regulated by the regulatory bodies, such as the Health Professional Council South Africa (HPCSA). These organisations act in the interests of the public by ensuring a high standard of training, education, and ethics, as well as by regulating the practice of healthcare professionals through professional regulations and peer group disciplinary action in the case of professional misconduct. All of these factors contribute to excellent performance of the professionals. The standards of the HPCSA and ethics of professionalism dictate that the practitioners deliver the service to the needy within their training field.

- Sub-theme 3.3: Appreciation for each other's skills as healthcare professionals and integration of care

During the interviews, professionals showed appreciation for each other's skills. This appreciation was noted from different members of the rehabilitation team. The team leader said: *"I have been in this rehabilitation service for more than four years; also, I have been at other hospitals in Pretoria. I can assure you that this team is very excellent in their work."*

A dietitian said: "*I have seen in this hospital the physiotherapist and the occupational therapist were working together."* A social worker opined: *"The efforts and the skills of this team member were very great, and I would like to appreciate this.*"

According to Burns and O'Connell (2012), the reason for formalised quality is man's internal desire to position himself/herself and to compare his/her performance with the ideal characteristics of professionalism. In this regard, the healthcare practitioners and organisations could become competitive (Burns & O'Connell 2012). The ideal characteristic of each health professional is to be able to perform and provide service under strenuous circumstances. Respect for each profession, appreciation, and encouraging of the professionals to prove themselves within the team will lead to improved performance and service delivery.

- Sub-theme 3.4: Existing referral systems for patients to different healthcare professionals and facilities

The findings revealed that the professionals use a referral system for patients to different healthcare facilities. Professionals either refer the patients to the nearest hospital or a rehabilitation centre according to the patient's needs and the availability of the rehabilitation centre for the patient in Gauteng.

This finding was confirmed by a participant who said:

"As the patient is from Capricorn, here we will be able to see him or her once every month. More than once is very difficult and we can't afford [it]. The patients who are referred back to their hospitals if they came back will be seen as outpatients only."

Another professional added:

"Sending those patients for rehabilitation in Pretoria need booking, and you may find they are fully booked for a year sometimes that is why those patients [are] sent to [the] nearest hospital or home while they are waiting for their turn to go for [the] specialised rehabilitation centre in Pretoria or Joburg."

The Department of Health and Social Development in South Africa developed a referral system between different level healthcare facilities to ensure continuous treatment to the patients according to his/her needs and availability (Department of Health 2003).

- Sub-theme 3.5: Explanation on treatment, management, and care for spinal cord injury patients that focus on the acute period

The healthcare professionals explained the process of treatment, management, and care for SCI patients, as well as why they focus on the acute phase of treatment. An occupational therapist stated:

"Again, we go back to the issue of six weeks bed rest, it is true we do bed transfer and physiotherapists do chest physiotherapy and other basic tasks but still the real rehabilitation work starts after the six weeks, and where the patient

needs [an] extra three weeks to be independent and ready for discharge. We know the need for bed rest for other patients besides the long hospital admission–all of this contributes and put more pressure on the doctor (in charge of the patient) to discharge the patient before the rehabilitation period is finished."

According to Emerich et al (2012), treatment of SCIs passes through three phases, namely the acute phase, sub-acute phase or transitional phase, and reintegration to community phase. The acute phase is often associated with a variety of concomitant injuries. Furthermore, persons sustaining SCIs become immediately vulnerable to a wide array of significant multisystem medical complications such as pneumonia, deep vein thrombosis (DVT), and pressure ulceration. It has been reported that the frequency of medical complications in SCI is inversely proportional to the quality of care available at the treatment facility. The rehabilitation programme, therefore, must develop treatment plans to prevent common medical complications during the acute phase of rehabilitation.

A recent meta-analysis of relevant literature concluded that the most important dimension of rehabilitation for people with SCI is the calibre and vision of the rehabilitation employees during the acute and sub-acute phases of rehabilitation (Emerich et al 2012).

4.6.4 Theme 4: Complications resulting from the lack of a rehabilitation programme for SCI patients

The findings of this study revealed that there are complications resulting from lack of rehabilitation centres and rehabilitation programmes in the Limpopo Province. Professionals verbalised that they faced a wide range of patients' complications while they attempt to fill the gap created by the absence of the rehabilitation centres and programmes in the province. These complications can be summarised into the following three sub-themes:

- Sub-theme 4.1: Patients' physical and psychological impairments resulting from a lack of rehabilitation centres and programmes

The findings of this study showed that one of the challenges of treating SCI patients is the patients' physical and psychological impairments resulting from a lack of rehabilitation centres and programmes. The physical and psychological impairment complications were outlined by a physiotherapist:

"One of the challenges is accepting the condition, most of these patients don't accept the idea that they will not be able to walk again or using their legs again. Actually, it is like stigma for them and lack of rehabilitation makes things worse. Let us say the first problem or challenge that [is] facing us is [the] psychological effect of the injury which needs rehabilitation which doesn't exist."

A social worker supported this opinion:

"Regarding the acceptance of the situation either by the patient or the community, by the way, this matter is having bilateral ends, like I mean the acceptance by the patient himself and the acceptance of the community to the patient, and here the role of the local social worker and psychologist and all other therapists during the rehabilitation period. Lack of acceptance of the condition required presence of psychologist and social worker within the rehabilitation team to overcome this matter; besides, other practitioners must also help toward overcoming the physical and psychological impairments."

The above result was also supported by the study carried out by House et al (2009). The authors concluded that psychological conditions are extremely common in SCI patients and result in up to 47% of SCI patients' experienced psychological impairment throughout the various stages of their hospitalisation. The highest rate was during the acute phase of hospitalisation. House et al (2009) reported that most of the patients considered their emotional needs insufficiently addressed by their rehabilitation team.

- Sub-theme 4.2: Patients' exposure to complications due to lack of rehabilitation centres and programmes

The findings of the study revealed that the lack of rehabilitation centres and programmes result in many complications. These complications were outlined by one of the participants who said:

"Really there are a lot of complications of those patients starting from the bedsores, prolonged urine catheter, kidney problems, sudden rise of temperature, chest complications, and other problems which need consultation from other doctors and other specialisation interference."

Another participant said*: "I think here in Polokwane our main challenge is equipment. During the final stage of rehabilitation, the equipment was sometimes unavailable, and the follow-up was poor. To follow these patients to their community to see whether they are integrated or not is poor and this is due to[the]financial situation of the hospital, so we were not able to do [an] outreach programme to follow these patients after discharge is ..."*

Bedsores and prolonged urine catheters were the major sources of complications for SCI patients in most of the developing and underdeveloped environments. The study conducted by Burns and O'Connell (2012) showed that pressure sores were the major cause of morbidity and mortality in resource-poor environments. A Pakistani study showed that 39.7% of the SCI patients were suffering from bedsores, while a Nigerian study showed that 60% of the patients with SCIs had experienced a pressure sore during some stage of their illness (Burns & O'Connell 2012).

- Sub-theme 4.3: Lack of healthcare professional's skills outlined as a risk resulting in patients' complications

In this study, professionals reported that they were struggling due to a lack of in-service training and workshops, which might up-skill the healthcare professionals who are caring for these patients. In Limpopo, because the province was under administration during the period of 2014–2015, there was

no budget for workshops and training. This situation resulted in a lack of skills and impacted a wide range of complications from which patients suffer.

One of the nurses reported that:

"*Not from the doctors but the management must at least increase the number of the enrolled nurses and professional nurses in orthopaedic ward at least if they are not able to create[a]special ward or unit for the spinal cord injury. The doctors must give more time in their round for thorough assessment to early discover the complications of the spinal cord injury patients instead of leaving this role to the professional nurses to discover the problem and 'til the doctor who will only write or fill a consultation form to another specialist. I understand the doctors' behaviour to some extent as they are not spinal cord injuries specialists. We need at least two spinal cord injuries specialists in this complex."*

Another nurse in the orthopaedic ward said:

"… (Silent for moment) … now we have orthopaedic doctors to manage the spinal cord injury patient although they don't have enough experience to manage those patients". Another physiotherapist said: *"… it will be of a great benefit if we can make training sessions for the therapist in the regional and other Hospital about the community integration, so they can help the whole community by integrating this important slide of the community."*

To stay current with advances in neuro recovery and rehabilitation following an SCI, team members should keep abreast of advances in SCI care in each of their respective disciplines so that the entire programme can benefit from the adaptation of care advances (Emerich et al., 2012).

4.6.5 Theme 5: Suggestions related to aspects that might lead to the provision of quality care to patients with spinal cord injuries

The study revealed that there were many challenges experienced during the rehabilitation and community integration of PLWSCI in the Limpopo Province. Professionals in the field of SCI rehabilitation provided suggestions related to

aspects that might lead to the provision of quality care to PLWSCI. These suggestions will be utilised in the second part of the study (the formation of a rehabilitation programme for PLWSCI) to assist in the successful reintegration of PLWSCI. The following subthemes emerged from this theme:

- Sub-theme 5.1: Significance of a specific period to start with rehabilitation of spinal cord injury patients

This study revealed that the professionals have mixed opinions concerning the period to start with the rehabilitation of SCI patients. Some of the professionals, especially doctors, thought that rehabilitation could be delayed until six weeks. The healthcare professionals who opined that the rehabilitation could be delayed explained that by recommending complete bed rest during the period of six weeks, as those patients will not be able to go for operations in the province.

One of the participants stated:

"Although the hospital didn't manage the programme of the rehabilitation according to[what]the protocol [is] supposed to be. For instance, we start the rehabilitation for the spinal cord injury patients after six weeks while according to the programme which is known to all the practitioners, we [are] supposed to start within three days after the operation day and we [are] supposed to start by the procedure for chest physiotherapy and static exercise [such] as [the] physiotherapist while other practitioners must also start early [such] as the dietician, psychologist, and so on."

Other professionals expected to start the rehabilitation procedure as early as possible according to the international protocol:

"We as [a] team expected to start our work from the first day but unfortunately in this hospital, if the patient has [a] spinal cord injury, he or she should stay on bed rest for six weeks before we can start. This is why some of our colleagues complain of delay of their interference with the patient, but this is the protocol. Unless if there is [an] urgent need for early interference, an example chest

physiotherapy with special and gentle care, like no turning over of the patient and so on."

An occupational therapist said: *"Yes, regardless of the type or location as far as [it]is[a]spinal cord injury,[the]patient must have bed rest for six weeks"*. A physiotherapist added: *"Again, we go back to the issue of six weeks bed rest, it is true we do bed transfer and chest physiotherapy and other basic tasks but still the real rehabilitation work starts after the six weeks, and where the patient needs [an] extra three weeks to be independent and ready for discharge."*

An assessment form and the multidisciplinary meetings should determine the period and when the interventions of the rehabilitation team should start (Sisto, Druin & Sliwinski 2009).

- Sub-theme 5.2: Emphasis on the importance of additional human and enough material resources

The findings of this study revealed that there is an urgent need for additional skills, professional employees, and extra resources to meet the rehabilitation needs of the province. A rehabilitation team leader said:

"Actually, yes. We need extra skills to meet our challenges in this situation. As the community integration [is] based on the rehabilitation, so really for a successful integration to the community we need to do a successful rehabilitation which need more and extra skills in this regard."

A physiotherapist also said:

"We need more physiotherapists and occupational therapists even in the clinics, so they can help those patients at the nearest point. I saw this in Northern Cape. There is a lot of physiotherapists and occupational therapist in the clinic and they help a lot and do a lot of integration because they know the people and the community members which can help to make it easy for everyone."

An orthotist who supported these suggestions said: *"You know these equipment we needed at the final stage like [a] tilt table, balance balls, callipers, raw*

materials and so on. Sometimes they stay longer in bed because they don't get braces to stand out of bed". A physiotherapist said: *"We are therapists, but we don't have equipment. If we have equipment, we can do it. I think also we need continuous training and development, to improve the skills of our therapists. If we get both advanced equipment and advanced training, we can do it – that is besides increasing the number of the therapists. We face a serious challenge of the staff. I hope this video is not going to national or the newspaper."*

According to Sisto et al (2009), skilled professionals and equipment are the main factors influencing successful rehabilitation and community rehabilitation. SCI patients in developing countries face numerous challenges, especially regarding equipment and spare parts (Burns & O'Connell 2012).

- Sub-theme 5.3: A need for training courses for management, treatment, and care of patients with spinal cord injury

The findings of the study showed that the healthcare professionals in Limpopo were not able to attend any training programmes, including workshops and training courses. One of the professionals said:

"The only time we received a workshop here on rehabilitation was in 2014. After that, the facilitator they didn't receive their money while the province [was] under administration, when we ask again for any workshop, they refused and asked us to pay them upfront."

A physiotherapist said:

"It will be of a great benefit if we can make training sessions for the therapist in the regional and other hospitals about the community integration, so they can help the whole community by integrating this important slide of the community." In-service training provides professionals more experience, refreshes their knowledge, and leads them to advancements in their field (Young et al., 2006).

- Sub-theme 5.4: A need for a special unit with specialist and community rehabilitation centres emphasised

The findings of this study emphasised the importance of an SCI unit and specialist rehabilitation centre for SCI patients in Limpopo. An occupational therapist noted: *"We need a rehabilitation centre here in Polokwane, or urgently we need [a] spinal unit here in this hospital and [the] other one in Mankweng"*.

In Gauteng, (the province closest to Limpopo) there are more than eight rehabilitation centres with a capacity of 150 beds (South African Association of Spinal Cord Association [SASCA] 2017), while Limpopo did not have one rehabilitation centre. This situation emerged the need for at least one rehabilitation unit or spinal cord injury unit for the Limpopo Province.

- Sub-theme 5.5: The importance of home visits

Participants from the disability organisations and SCI patients demonstrated the importance of home visits. One of the participants, a physiotherapist, opined: *"The follow-up again, I want to emphasise in, we do write referrals to the nearest hospital or local hospital and therapist there, but follow-up is zero. We really don't know what happens to those patients after that."*

Another participant said concurred: *"There is no follow-up, as we mentioned earlier, this is one of the reasons for this gap. Besides we assume the therapist there at the local hospital is doing the optimal work. Absence of the outreach programme also contributes a lot in this regard."*

A social worker echoed this statement regarding follow-up: *"Also the follow-up is poor. To follow these patients to their community to see whether they are integrated or not is poor and this is due to [the] financial situation of the hospital, so we were not able to do [an] outreach programme to follow these patients after discharge …"*

Home visits are necessary in providing the bridge between the hospitalisation period and community integration (Charlifue & Gerhart 2004). A rehabilitation service for SCI patients should shift even more from hospital rehabilitation to the

community. The goals of community integration are to restore, achieve, or maintain physical or cognitive function or occupational performance in PLWD, their family members, and caregivers in their environment within the community (Charlifue & Gerhart 2004). There are several benefits of home visits, such as it shortens the length of the hospital stay, provides service convenience to clients, promotes better therapy effectiveness, and offers greater relevance for patients to reintegrate into the community (Welage & Liu 2008).

4.6.6 Theme 6: Experiences for patients with SCIs as observed by healthcare professionals

SCI patients are the main partners of the rehabilitation process; therefore, the experiences of patients with SCIs are important. In this study, the researcher also took the ideas and experiences of patients with SCI as observed by the healthcare professionals and patients. In this theme, the experiences of patients with SCI as observed by healthcare professionals are divided into the following sub-themes:

- Sub-theme 6.1: Existence of self-stigmatisation portrayed by patients

The findings of this study revealed the existence of self-stigmatisation portrayed by patients. Professionals in the rehabilitation team described the situation. One of the participants pointed out:

"The idea that they will not be able to walk again or using their legs again, actually it is like stigma for them. Let us say the first problem or challenge that [is] facing us is [the] psychological effect of the injury."

Other participants held positive views on the issue of stigmatisation. The head of a disability organisation stated:

"In this organisation we run a programme of community-based rehabilitation for people with disability, because we believe that being disabled and [if you] receive rehabilitation, your life will go back to normal and you don't feel discriminated[against]or isolated or other feelings that [a] disabled person may feel in [a] normal basis."

These findings are supported by an Australian study, which showed that poor continuity of care could have significant physical and psychosocial implications for PLWSCI and their families (Welage & Liu 2008).

- Sub-theme 6.2: Existing changes at different levels of patients' lives observed

The study found that there were changes in the SCI patients' lives. These changes usually occurred at various levels after the injury. A PLWD said:

"You must understand that most of these people living with disability are living under the poverty line. Most of the houses they are stayed in they are not accessible and is not prepared for [a] disabled person. And if [you] check the people with disability, they are not at work; they are not employed. Even if you are employed, the life of the disabled person is very expensive … the needs are not the same".

Another participant added: *"Some people they need (nappies) for example, because they cannot control them self or at least [a] urine catheter which needs to be changed every time. This beside the infection and the medication and the pain medication."*

PLWSCI and their families have more responsibilities because they need to adjust to a new and different life (Welage & Liu 2008). New adjustments in the home include: the kitchen, the bathroom, and the passages between the rooms to make it accessible to the person with SCI. PLWSCI have additional special needs such as mobility devices, nappies, periodical clinical visits, and many other products or equipment which is extremely expensive.

- Sub-theme 6.3: Challenges experienced by patients at various levels of life observed

The findings of this study showed that SCI patients experienced challenges at several levels of their lives. Numerous SCI patients participated in this study and conveyed their experiences as a PLWSCI. One SCI patient said:

"You know, if the disabled person used to face the community from the beginning, then it will not be a problem for him to interact with the people, but if the person didn't accept his disability or scared from seeing the community or people outside his place, then this person will be having a lot of problems".

A manager of a disability organisation added:

"… for example, if I want to attend any function, I might be limited from participation because you may find the venue is not accessible to wheelchairs. If I [was] invited to any function, before I confirm my attendance, I used to ask if the venue is accessible to me or not. Also, [the] bathroom must be suitable for [a] disable person and accessible to [a] wheelchair. In my work in this organisation, I have seen a lot of men and women, when their rehabilitation was not done properly; I have seen their life has been shattered and ended there."

Another participant continued:

"In the rural area, mostly these venues are not accessible, that is why the disabled people attend[ing] is weak. In my village, I made it clear to the pastor that the church must be accessible not only for me but for all disabled people, and they respond[ed] to my request. I believe in the fact that (accessibility for all). For example, if there are steps in a certain venue and there is a ramp, you will find an elderly person, a pregnant woman, children, and disabled person using the ramp."

Another SCI patient said: *"Accessibility [is] one of the major … major … major issues for the SCI people."* Another participant identified one of the challenges as follows:

"Like marriage, a very small number of people accept to marry a person with spinal cord injuries, unless if [the] spinal cord injury person can marry [an]other spinal cord injury person. I have seen a lot of women–after injury, they lose their men. [I] didn't know what those men think whether this woman is no more useful or what, but it gives me a lot of pain when I see this situation. I would like to say to the injured lady; even if you are not injured, such a man will not help you in

the long future of life, because if he leaves you because of your injury, he might leave you for any other reason."

An SCI patient who works for an SCI organisation said:

"… (mmm) … because of the legislations and the community awareness, the environment has improved. People start to understand the disability and the spinal cord injury that can happen to anyone and the disables person have no part in being like this and this person has the right to live his life free as any normal person. But still, there is[a]long way to go because [of] the people's attitude toward the disabled person; people still doubting the ability of the disabled person."

This finding has been confirmed by many studies around the world (Chan & Chan 2005; Kendall et al., 2003). An Australian study found that poor continuity of care might have significant physical and psychosocial implications for individuals with SCI as well as their families (Kendall et al., 2003). PLWSCI often have limited financial resources to engage in social activities, and they suffer from social exclusion (Kendall et al., 2003). Disability organisations in Sri Lanka reported that buildings, including railway stations and even hospitals, were inaccessible to their members (Chan & Chan 2005). A US study revealed the unequal distribution of resources throughout the community, causing difficulties to PLWSCI in rural areas of the US, especially as it pertains to accessibility, transportation, and social participation (Charlifue & Gerhart 2004).

- Subtheme 6.4: A need for regaining importance for life desired by patients

One of the participants concluded: *"… [the] person as well must be having a vision in this life and aim to achieve so the person's life must have a meaning. To me, we as people with disability, we need to stand up for our rights".*

Organisations, therapists, and the RAF need to collaborate to contribute funding to people PLWSCI so that they can improve their quality of life (Weerts &

Wyndeale 2011). The police- and security industry has a role to play in ending the violence that often leads to SCIs (Weerts & Wyndeale 2011).

PLWSCI must understand that the injury is not the end of one's life; there is still life after injury (Burns & O'Connell, 2012). PLWSCI who want to return to school can do so. PLWSCI who have a family can still take care of their families. It is the role of the psychologist and social worker to prepare the PLWSCI for this situation. If community integration and rehabilitation are improved, many families and people could be saved (Weerts & Wyndeale 2011).

4.7 Summary

This chapter discussed the findings of phase 1 of the study. The quantitative findings were presented, followed by the qualitative findings based on the information-rich interviews with participants. The findings indicated an urgent need for the implementation of a rehabilitation programme to enhance a successful and better community reintegration for PLWSCI. The quantitative results also highlighted the importance of home visits and following up on the patients after they have returned to their communities.

The qualitative findings were presented according to six themes that were also divided into several sub-themes. The six themes highlighted: 1) the challenges experienced by healthcare professionals caring for PLWSCI; 2) experiences of healthcare professionals related to caring for PLWSCI; 3) complications resulting from a lack of a rehabilitation programme for SCI patients; 4) suggestions related to aspects that might lead to the provision of quality care to patients with SCIs; 5) suggestions related to aspects that might lead to the provision of quality care to patients with SCIs; and 6) experiences of SCI patients as observed by healthcare professionals.

The chapter concluded with a discussion of the qualitative findings of this study. Both results of the quantitative and qualitative data form the basis for the suggested rehabilitation programme that will be consolidated and discussed in the next chapter.

CHAPTER FIVE

PHASE 2: DELPHI STUDY

5.1 Introduction

The previous chapter focused on phase 1 of the study that focused on the presentation and interpretation of the results of the study. This chapter discusses the procedure used to reach consensus on the rehabilitation programme for the appropriate community integration for PLWSCI in the Limpopo Province. The Delphi technique was used in this phase of the study.

The main objective of this study was to design a rehabilitation programme for PLWSCI in the Limpopo Province to enhance proper community integration for such an important component of the community. The programme aimed to link the ideas of the patients (PLWSCI) and the scientific standards in South Africa through the academic personnel in the field, along with the possibilities that professionals can achieve.

The ability to making decisions and finalising such a programme in a situation where there is conflicting or a deficit of information has led to the increased use of consensus methods, namely brainstorming, the nominal group technique, and the Delphi technique (Hsu & Sandford 2007). The Delphi technique employs multiple iterations that are designed to develop a consensus of opinions concerning a specific topic (Adams 2001; Skulmoski, Hartman & Krahn 2007). The number of participants in the Delphi study where the group is homogeneous should be between 10 to 15 people and could yield sufficient results (Skulmoski et al 2007).

The Delphi study is characterised by the ability to provide anonymity to the respondents or experts, a controlled feedback process that enables the experts to reassess their responses, and the suitability of a variety of statistical analysis techniques to analyse and interpret the data (Adams 2001). Due to its many advantages, the Delphi technique has been applied in many fields such as

public administration, economics, business, resource and environmental management, education, healthcare, energy policy, and urban and regional analysis (Miller 1993).

5.2 Methodology

A three-round e-Delphi technique was employed in the current study. Experts in the field of rehabilitation and academic personnel in the field were selected from academics and healthcare practitioners who were involved in the rehabilitation of SCI patients in Limpopo.

5.3 Procedure

The selection procedure as outlined by Okoli and Pawlowaski (2004) was adapted as illustrated in Figure 5.1.

Step 1: Prepare knowledge resource nominated worksheet (KRNW)	Identify relevant disciplines, skills, academics, and practitioners Identify relevant academic and practitioner literature
Step 2: Populate KRNW with names	Write the names of individuals in relevant disciplines Write the names of individuals from academic and practitioner literature
Step 3: Rank experts	Create sub-lists Categorise experts according to appropriate list/or area of specialisation
Step 4: Invite experts	Invite experts for each panel, with panels corresponding to each discipline Stop soliciting experts when each panel size is reached

Figure 5.1: Procedure for selecting experts

Source: Okoli and Pawlowaski (2004)

A purposively selected panel of experts (professionals and academic personnel) were invited to participate in the Delphi study. A group of rehabilitation professionals involved in the rehabilitation of SCI patients and academic experts from different universities that offer rehabilitation were selected for the Delphi study. An equal number of professional experts and academic experts were selected. The Delphi participants were required to meet four “expertise” requirements, including knowledge and experience with the issue, capacity and willingness to participate, sufficient time to participate in the Delphi study, and effective communication skills (Skulmoski et al 2007).

In this study, twelve (12) participants were selected. Half of them (6) were academic experts who were familiar with the content, and they were from universities that offer physiotherapy and occupational therapy programmes in Gauteng, i.e. Sefako Makgatho Health Sciences University (SMU), University of Pretoria, and University of Witwatersrand. The other half (6) were professionals who work in the SCI rehabilitation unit, both at outpatient and inpatient units of the Mankweng hospital complex. An invitation to participate was sent via e-mail. The information sheet and consent forms were included in the invitation (Refer to Appendix 3A & 3B).

A telephonic conversation with the participants was used to confirm their participation and to obtain their demographic data such as age, gender, highest qualification obtained, current professional practice, and the number of years’ experience in the field. Informed consent was requested from 30 experts. Twelve (12) of these consented to participate. No reason was given by the experts who declined. The questionnaire was developed from the qualitative and quantitative results of this study and sent to the participants in the first round of the Delphi study. The experts returned the questionnaire after six weeks. Descriptions of the participants are outlined in Table 5.1. The mean age was 44.3 years (SD = 5.1), while the mean years of practice were 18.5 years.

Table 5.1: Demographic characteristic of panel of Delphi study (n = 12)

Table5.1: Demographic characteristic of panel of Delphi study n=12

ID code	Gender	Age (years)+ gender	Highest Qualification	Current Occupation	Years of experts	Role in Rehabilitation of PLWSCI
1	Female	51	PhD	Head of Dept Professor, lecturer	20	• Head of academic department related to the rehabilitation • Researcher in rehabilitation of SCI • Teaching rehabilitation subject at university level
2	Female	48	PhD	Head of Dept Professor, lecturer	15	• Head of academic department related to the rehabilitation • Researcher in rehabilitation of SCI • Teaching rehabilitation subject at university level
3	Male	40	Doctorate	Physiotherapist	15	• Researcher in the rehabilitation field • Running a rehabilitation practice in the province
4	Female	45	PhD	Psychologist	16	• Lecturer, researcher
5	Male	53	Master degree	Physio	25	• Ex-provincial coordinator of physiotherapy and Deputy manager of physiotherapy in the province • Running a rehabilitation originated private Practice • Researcher
6	Male	38	Master	Physio	17	• Researcher , • Part of the multidisciplinary team in the province
7	Male	44	Master	Senior lecturer	15	• Lecturer at an academic department Related to the rehabilitation • Researcher in rehabilitation of SCI • Teaching rehabilitation subject at university level
8	Female	40	B.sc. Degree	DM Physio	16	• Deputy Manager physiotherapy dept In a provincial hospital
9	Female	39	Degree	OT	15	• researcher • Practitioner in the field
10	Male	40	Degree	Chief Physio	18	• Working in Rehabilitation of patients as a physiotherapist in Limpopo for 15 years
11	Female	50	Master degree	consultant	22	• Consultant occupational therapist with road traffic fund • Practitioner in the field of rehabilitation
12	Female	44	Degree	OT	13	Managing SCI patients in polokwane –mankweng complex for the last (10)years

5.4 Selection criteria

The inclusion criterion for the professional participants was that participants must have worked in the rehabilitation of SCI patients for at least two years. Professionals who never worked in the Polokwane or Mankweng complex were excluded. Academic experts had to have at least a master's degree and vast experience of rehabilitation in their respective fields.

5.5 Results of first round of the Delphi study

The first round of the Delphi study involved sending the questionnaire to the 12 experts. All the experts responded, making the response rate 100%. The results of round 1 were analysed according to the statistician guidance, e.g. qualitative coding or statistical summarising into medians plus upper and lower quartiles. The results of the thematic analysis are presented in tabular format.

5.5.1 Formation of the rehabilitation team

The experts were of the opinion that the rehabilitation team must include a physiotherapist, occupational therapist, dietician, social workers, psychologist, speech therapist, nurses, and doctors. Experts gave several reasons for including all healthcare professionals in the team. Table 5.2 shows the statistical analysis of their reasons.

Table 5.2: Reasons for including all health professionals in the rehabilitation team

Emerging themes	N	%
Holistic management of the patient	7	58.33
Multidisciplinary approach	3	25
Speedy recovery	2	16.67

The non-professional team experts' opinions were summarised in Table 5.3. It was noticeable that experts did not agree with including the community member in the rehabilitation team for various reasons as shown in Table 5.3.

Table 5.3: Body to be included in the rehabilitation team other than the healthcare professionals

Body to be included	Reason	N	%
Family of the patients	To deal with patient at home	12	100
Caregivers – CBRW	To avoid preventable medical complications at a later stage, and to speed up community reintegration	12	100
Stage family member should be included	Family must be included from day one to deal and cope with their member after discharge	12	100
Religious group	Spiritual support Needed, but not to give high hope on their condition	102	83.3 16.67
Community members	Must not be included for privacy reasons Must only provide opinion to the family from point of experience Not a necessity	6 2 4	50 16.67 33.3

5.5.2 Distribution of powers

All the experts, 12 (100%), agreed that rehabilitation must start immediately and that every professional must have his/her plan to deal with acute, sub-acute, and chronic case rehabilitation. All the experts, 12(100), agreed on the necessity of a team co-plan for the rehabilitation of SCIs to achieve the long-

term rehabilitation goals and to reach perfect community integration of the patient. Experts agreed that handover must occur between the practitioners in the same profession and the handover or referral must include summary notes on the patient's functional level or achievements.

5.5.3 Documentation

Most of the experts (75%) agreed that documentation must include the patient's details, present his/her medical history, socioeconomic history, past medical history, investigations done, tests, and management done (conservation as well as non-conservation), findings, diagnosis, assessments, medication, and further plans. Some of the experts (25%) suggested that the documentation must include a medico-legal report, for example, a detailed description of the wound, disabilities, and the future of the injury.

5.5.4 Mobility and assistive devices

The suggestion of the experts regarding mobility and assistive devices a summarised in Table 5.4.

Table 5.4: Experts' suggestions regarding wheelchair distribution

Theme	**N**	**%**
When giving patient's devices (such as a wheelchair), we must consider the rural setting. Patient must be able to manoeuvre the device for all types of environments.	11 1	91 8.3
Wheelchair accessories should include hand protectors, wheelie, mitts, gloves sponge, and matt to prevent skin sores.	12	100
Wheelchairs are not accessible for all patients. I don't know if wheelchairs are accessible for all patients or not	102	83 16.67
Wheelchairs accessories are not accessible for all patients I don't know if they are accessible or not	102	83 16.67

The experts suggested three solutions for the challenges regarding the wheelchair accessibility challenges and the accessories of wheelchair challenges. Table 5.5 shows the experts suggestions to solve the challenges of mobility and assistive device distributions to the needy.

Table 5.5: Experts' suggestions to solve the challenges of mobility and assistive device

Suggestion	**N**	**%**
RAF must take responsibility in this matter	6	50
All patients should be inside the medical aid umbrella, and the medical aids take responsibility	4	33.3
Disability organisation should take the responsibility	2	16.67

5.5.5 Home programme

Experts in the first round agreed on the following items of the home programme for SCI patients after discharge. Experts did not agree on who should introduce the patient's situation to the community. Table 5.6 outlines the programme and the percentage of agreements among the experts.

Table 5.6: Home programme

Home programme items	N	%
Home programme must be clear and include the type, frequency, and safety	12	100
Written home programme should be incorporated into the rehabilitation of the patient	12	100
Multidisciplinary team must compile the programme as a team	12	100
Caregiver and community nurse should monitor the programme homework	12	100
Home visit is important to evaluate the home programme	12	100
Introduction of the patient situation to the community must be done by Psychologist and/or Social worker	7	58.3
Whole team must introduce the situation to the community	5	41.67
I don't know	1	8.33
Duration of the rehabilitation should be at least 6 weeks	3	25
Duration of rehabilitation should be 12 weeks to let the vertebra and soft tissue heal	5	41.67
Duration of rehabilitation depends on the treatment of the injury and the speed of recovery	4	33.3
Planned programme with clear goals and the collective work of the rehabilitation team should protect the patient being over-exercised or under-exercised	12	100

5.5.6 Self-care

All experts agreed that the rehabilitation team should teach the patient during the rehabilitation period how to wash and dress himself/herself, transfer from the bed to wheelchair, self-padding and skin check, and wheelchair mobility.

Experts agreed that the rehabilitation team should monitor the patient's integration into the community as a team.

5.5.7 Outcome of successful rehabilitation

Experts suggested indicators for successful rehabilitation. Experts' opinions about the indicators are shown in Table 5.7.

Table 5.7: Outcome of successful rehabilitation programme

Indicator	**N**	**100**
The patient should be as independent as possible in all self-care areas allowed by existing muscle function appropriate for his/her level of injury	12	100
The patient must have orthopaedic clearance for gait training	12	100
The patient must be willing to spend the necessary four to six weeks in the programme and to work the full five days a week to gain the required strength and train new functions I don't know	9 1	75.6 8.33
Patient's skin should be free of bedsores	12	100
Patient should express and understand the limitations of gaiting I don't know	11 1	91.6 8.33
During the sub-acute phase of rehabilitation after an SCI, the rehabilitation team will work on getting around, bathing, dressing, skincare, and bowel and bladder management	12	100
On discharge, paraplegic patient should be able to wash, dress, feed himself as well as self-padding, skin check, and wheelchair mobility	12	100
On discharge, tetraplegia (depending on the level of injury) should be able to wash, feed, dress himself/herself as well as wheelchair mobility/electrical wheelchair	12	100

5.6 Results of the second round of the Delphi study

The rehabilitation programme for PLWSCI in Limpopo in phase 2 of the Delphi study was designed based on the emerging themes from the Delphi panel responses in round 1. The response rate was 100% as all of the twelve (12) experts who consented to participate in the study responded to the round 2 Delphi study. A consensus from the expert opinions was set at 70% or more (Hasson et al 2000; Skulmoski et al 2007).

The second round of the Delphi study aimed to reach a consensus on the content of an appropriate rehabilitation programme for PLWSCI to reach a successful community reintegration for PLWSCI. All the participants (*n* = 12, 100%) consented that the programme should concentrate on the sub-acute phase or the transitional phase before discharge home or to the community. All the participants (*n* = 12, 100%) agreed that the programme should clearly identify the people who should be included in the multidisciplinary rehabilitation team. They agreed that the multidisciplinary rehabilitation team should include a rehabilitation doctor, rehabilitation sister, physiotherapist, occupational therapist, dietician, psychologist, social worker, orthotist, speech therapist, caregiver, religious group (for spiritual support), and a family member. The majority of the experts (n = 11, 91.6%) refused the idea of including community members in the team.

All the participants (*n* = 12, 100) agreed on the distribution of power, documentation, and referral letters after the sub-acute phase of rehabilitation. They agreed that the rehabilitation process in the acute phase must start immediately after restoring the patient's medical condition. Each professional must have his/her plan to deal with the acute, sub-acute, and chronic rehabilitation plan. In all phases of rehabilitation, a team co-plan is important for the rehabilitation of the SCI patient to achieve the long-term goals of rehabilitation and to reach perfect community integration.

Regarding the handover of the cases (patients), all the participants (*n* = 12, 100%) agreed that handover must happen between the practitioners in the

same profession. They agreed that handover must be professionally done through referral letters. Referral letters must include summary notes about the patient's functional level and/or achievements. The majority of the participants (*n* = 11, 91.6%) agreed that documentation must include the patient's details, present and past medical history, socioeconomic history, investigations and tests done, assessments, findings and diagnosis, management, medications, and further plans.

Experts recommended some regulatory majors regarding mobility and assistive devices. All the participants (*n* = 12, 100%) recommended that wheelchairs must be accessible for all patients and wheelchair accessories should include hand protection, wheelie, mitts, gloves sponge, and matt to prevent skin sore. The majority (*n* = 10, 83.33%) of the participants agreed that when providing a patient with a device (such as a wheelchair), one must consider rural settings. The majority of the participants (*n* = 10, 83.33%) agreed that at the end of the sub-acute phase, the patient must be able to manoeuvre with the walking assistive device, whether it is a wheelchair or crutches, on all types of environments.

Regarding the challenge of availability of wheelchairs and walking assistive devices, experts recommend that all patients should be inside the medical aid umbrella (*n* = 12, 100%), disability organisation (*n* = 11, 91.6%), and RAF should share responsibility for the availability of the wheelchairs for the PLWSCI due to road accidents (*n* = 10, 83.3%).

All the participants reached a consensus on home programme items (*n* = 12, 100%). They recommended that a written home programme should be incorporated into the rehabilitation of the patient during the sub-acute phase. The home programme must be clear and include the type, frequency, and safety. A multidisciplinary team must compile the programme. The caregiver and community nurse should be trained to monitor the programme homework. The home visit is important to evaluate the home programme.

Experts agreed that the duration of the sub-acute phase of the rehabilitation programme should depend on the treatment of the injuries and the speed of recovery (*n* = 12, 100%). They all agreed (*n* = 12, 100%) that a planned programme with clear goals and collective work of the rehabilitation team should protect the patients from becoming over-exercised or under-exercised. A consensus was reached among most of the experts (*n* = 10, 83.33%) that patients should be introduced to the community by the whole team and not only by the psychologist or social workers.

All the experts (*n* = 12, 100%) agreed that during the sub-acute phase, the rehabilitation team should teach the patient how to wash and dress himself/herself, transfer from bed to wheelchair and back to bed, self-padding, skincare, and wheelchair mobility. The majority of the participants (*n* = 10, 83.33%) recommended that the rehabilitation team should monitor the patient's reintegration into the community as a team.

Regarding the outcome of a successful rehabilitation programme, experts agreed (*n* = 12, 100%) that a successful rehabilitation programme for PLWSCI should be indicated by the patient being as independent as possible in all the self-care areas allowed by existing muscle function appropriate for his/her level of injury. They agreed (*n* = 12, 100%) that the patient must have orthopaedic clearance for gait training. The patient's skin should be free of bedsores (*n* = 12, 100%). The patient should express and understand the limitations of gaiting (*n* = 12, 100%). During the sub-acute phase of rehabilitation after the SCI, the rehabilitation team will work on gaiting around, bathing, dressing, skincare, diet, feeding himself/herself, and bowel and bladder management (*n* = 11, 91.6%). On discharge, paraplegic patients should be able to wash, dress, feed himself/herself, padding, skin check, as well as ambulation using the suitable assistive device (*n* = 11, 91.6%). On discharge, tetraplegic patients (depending on the level of injury) should be able to wash, feed, dress, and pad himself/herself and have a wheelchair or electric wheelchair mobility.

5.6.1 Formation of the rehabilitation team

The people who should be included in the rehabilitation team are listed in Table 5.8.

Table 5.8: The content of rehabilitation programme to enhance community integration for PLWSCI in Limpopo Province after Delphi study round 2

Item	N (%)	Opinion/advice
The rehabilitation team should include a rehabilitation doctor, rehabilitation sister, physiotherapist, occupational therapist, dietician, psychologist, social worker, orthotist, speech therapist, caregiver, religious group (for spiritual support), and family members.	12 (100)	Multidisciplinary approach will enhance holistic management approach and speedy recovery.

5.6.2 Distribution of powers

Items	N (%)	Opinion/advice
Rehabilitation process in the acute phase must start immediately after restoring the patient's medical condition Each professional must have his/her plan to deal with acute, sub-acute, and chronic rehabilitation plans In all phases of rehabilitation, a team co-plan is important for the rehabilitation of the SCI patient	12 (100)	The long-term goals of the rehabilitation must be to reach perfect community integration
Handover must be professionally done through referral letters. Referral letters must include summary notes about the patient's functional level and/or achievements.	12 (100)	
A team co-plan is important for the rehabilitation of SCIs.	11 (91.6)	

5.6.3 Documentation

Items	n(%)	Opinion/advice
Documentation must include the patient's details; present and past medical history, socioeconomic history, investigations and tests done, Assessments, findings and diagnosis, management done, Medications and further plan.	11(91.6%)	Copy of the reference letter must be kept on the file

5.6.4 Mobility and assistive devices

Items	N (%)	Opinion/advice
Wheelchairs must be accessible to all patients.	12 (100)	
When providing the patient with devices (such as a wheelchair), consider rural settings. The patient must be able to manoeuvre the device for all types of environments.	10 (83.33)	
At the end of the sub-acute phase, the patient must be able to use his/her assistive device whether it is a wheelchair or crutches for all types of environments.	10 (83.33)	
Wheelchair accessories should include hand protectors, wheelie, mitts, gloves, sponge, and matt to prevents skin sores.	10 (83.33)	
To secure wheelchairs and walking assistive devices, all patients should be inside the medical aid umbrella.	12 (100)	
Disability organisations should share responsibility.	11 (91.6)	
RAF should share responsibility for the availability of wheelchairs for the PLWSCI due to road accidents.	10 (83.3)	

5.6.5 Home programme

Home programme items	**N (%)**	**Opinion/advice**
A written home programme should be incorporated into the rehabilitation of the patient during the sub-acute phase. Home programme must be clear and include the type, frequency, and safety. A multidisciplinary team must compile the programme as a team. Caregiver and a community nurse should be trained to monitor the programme homework. Home visit is important to evaluate the home programme.	12 (100)	
The duration of the sub-acute phase of the rehabilitation programme should depend on the treatment of the injuries and the speed of recovery. A planned programme with clear goals and collective work of the rehabilitation team should protect the patients from being over-exercised or under-exercised.	12 (100)	
Patients should be introduced to the community by the whole team, not by the psychologist or social workers only.	10 (83.33)	

5.6.6 Self-care

Items	**N (%)**	**Opinion/advice**
During the sub-acute phase, the rehabilitation team should teach the patient how to wash and dress himself/herself, transfer from bed to wheelchair and back to bed, self-padding, skincare, and wheelchair mobility.	12 (100)	
The rehabilitation team should monitor the patient's reintegration into the community as a team.	10 (83.3)	

5.6.7 Outcome of successful rehabilitation

A successful rehabilitation programme for PLWSCI should include the following:

Indicator	**N (%)**	**Opinion/advice**
The patient should be as independent as possible in all the self-care areas allowed by existing muscle function appropriate for his/her level of injury. The patient must have orthopaedic clearance for gait training. The patient's skin should be free of bedsores. The patient should express and understand the limitations of gaiting.	12 (100)	
During the sub-acute phase, the rehabilitation team will work on gaiting around, bathing, dressing, skincare, diet, feeding him/herself, and bowel and bladder management.	11 (91.6)	
On discharge, paraplegic patients should be able to wash, dress, feed himself/herself, pad himself/herself, skin check, as well as ambulation using the prescribed assistive device.	11 (91.6)	
On discharge, tetraplegic patients (depending on the level of injury) should be able to wash, feed, dress, pad himself/herself, and wheelchair/electric wheelchair mobility.	11 (91.6)	

5.7 Results of the third round of the Delphi study

A few sections that experts could not reach consensus on besides some suggestions came from the experts in round 2 and were included in round 3 of the Delphi study. A consensus was not reached on the duration of the sub-acute phase of the rehabilitation programme. Only two suggestions were sent in round 3 in this regard.

In the documentation section, experts could not reach consensus regarding the copy of the reference letters between the practitioners or whether to keep a copy in the patient's file or at the department's records. In this regard, only two suggestions were presented to the experts. Nine (9) out of twelve (12) experts responded at the end of four weeks, which gave a rate of 75%. Experts could not determine the specific duration and intensity of the rehabilitation programme in the sub-acute phase. Experts, however, did reach a consensus (*n* = 9, 75%) that the sub-acute phase of rehabilitation depends on (i) speed of recovery, (ii) response of the patient, (iii) age of the patient, (iv) patient's lifestyle before the injury, and (v) injury location and type. Experts agreed (*n* = 9, 75%) that a copy of the referral letters should be kept in the patient's file. A consensus on this point was reached after a telephonic conference with the experts (*n* = 9, 75%). The reason behind this decision was the patients' privacy that was protected by law.

Table 5.9: Results of the Delphi round 3, finalising duration of the sub-acute phase of the rehabilitation programme and documentation

Items	**N**	**(%)**
Patient must be willing to spend the necessary time during the rehabilitation programme to gain the required strength and train new functions	9	75
The duration of the sub-acute phase of rehabilitation depended on: speed of recovery; (ii) response of the patient ;(iii) age of the patient; (iv) patient's lifestyle before the injury; and (v) injury location and type.	9	75

5.7.1 Documentation

Items	Yes	No
Copy of the refereeing letters between the practitioners must be kept in the patient file	9	75

5.8 Summary

The experts agreed that the rehabilitation programme to enhance community integration for people with SCIs in the Limpopo Province should include the identification of the rehabilitation team, distribution of powers between the team members, documentation and referral letters, mobility, assistive devices, sub-acute rehabilitation tasks, home programmes, and the outcome of the successful rehabilitation.

Experts agreed that the rehabilitation team should include a rehabilitation doctor, rehabilitation sister, physiotherapist, occupational therapist, dietician, psychologist, social worker, orthotist, speech therapist, caregiver, religious group (for spiritual support), and family members. A multidisciplinary approach should enhance the holistic management and speedy recovery.

Experts consented that each professional must have his/her plan to deal with an acute, sub-acute, and chronic rehabilitation plan. The rehabilitation process in the acute phase must start immediately after restoring the patient's medical condition. In all phases of rehabilitation, a team co-plan is important for the rehabilitation of SCI patients. Furthermore, community reintegration for PLWSCI should be the long-term goals of rehabilitation for all the health care professionals.

The experts suggested that the documentation must include the patient's details such as present and past medical history, socioeconomic history, investigations and tests done, assessments, findings and diagnosis, management done,

medications, and further plans. A copy of the reference letter must be kept in the file. Referral letters between the professionals must include summary notes about the patient's functional level and/or achievements. A team co-plan is important for the rehabilitation of SCI.

Experts agreed that wheelchairs must be accessible for all patients. Wheelchair accessories should include hand protection, wheelie, mitts, gloves, sponge, and matt to prevent skin sores. At the end of the sub-acute phase, the patient must be able to use his/her assistive device, whether it is a wheelchair or crutches, for all types of environments. To secure wheelchairs and walking assistive devices, the programme suggested that all patients should be inside the medical aid umbrella. Disability organisations and the RAF should also share responsibility for the availability of wheelchairs for the PLWSCI due to road accidents.

Experts consented that a written home programme should be incorporated during the rehabilitation of the patient in the sub-acute phase. The home programme must be clear and include the type, frequency, and safety. A multidisciplinary team must compile the programme as a team. During the sub-acute phase of rehabilitation, the caregiver and community nurse should be trained to monitor the programme homework. The duration of the sub-acute phase of the rehabilitation programme should depend on the treatment of the injuries and the speed of recovery.

A planned programme with clear goals and collective work of the rehabilitation team should protect the patients from being over-exercised or under-exercised. Patients should be introduced to the community by the whole team, not only by the psychologist or social workers.

Furthermore, experts suggested that during the sub-acute phase, the rehabilitation team should teach the patient how to wash and dress himself/herself, transfer from bed to the wheelchair and back to bed, self-padding, skincare, and wheelchair mobility. The rehabilitation team should monitor the patient's reintegration into the community as a team.

At the end of the programme, the patient should be as independent as possible in all self-care areas. The patient must have orthopaedic clearance for gait training, and his/her skin should be free of bedsores. The patient should express and understand the limitations of gaiting and should have realistic expectations. On discharge, the paraplegic patient should be able to wash, dress, feed himself/herself, pad, and skin check as well as ambulation using the prescribed assistive device. On discharge, tetraplegic patients (depending on the level of injury) should be able to wash, feed, dress, pad himself/herself, and have a wheelchair or electric wheelchair mobility.

CHAPTER SIX

DISCUSSION, CONCLUSION, AND RECOMMENDATIONS

6.1 Introduction

The previous chapter dealt with phase 2 of the Delphi study. This chapter provides a discussion of the study, concludes the study, and provides recommendations of the study. The primary aim of this study was to design a rehabilitation programme to enhance community reintegration for PLWSCI in the Limpopo Province of South Africa. This aim was achieved in phase 2 of the study by designing a rehabilitation programme with special focus on the sub-acute phase or the transitional phase before integrating back into the community. In phase 1, the study aimed to determine how PLWSCI were currently integrated into their communities in rural areas of Limpopo. To achieve this aim, the study tended to describe the challenges facing PLWSCI in the province regarding rehabilitation and integration into the community and to identify the physical barriers of the rehabilitation for PLWSCI in Limpopo.

6.2 Description of the challenges facing PLWSCI in the province regarding rehabilitation and integration into the community

Globally, physical independence, mobility, occupation, social integration, economic self-sufficiency, limited community resources, and access to medical and social services were the main challenges facing rehabilitation and community reintegration for PLWSCI (Burns & O'Connell 2012; Charlifue & Gerhart 2004). The transition from acute rehabilitation to home is especially critical because people are confronted with many obstacles as they attempt to resume participation in the community (Charlifue & Gerhart 2004). For the majority, rehabilitation is "some form of exercises" rather than a multidisciplinary team approach. Others do not consider a complete SCI worthy of any active management and rehabilitation (Rathore et al 2012).

The challenges faced by PLWSCI differed between developed and low-resource countries (Burns & O'Connell 2012). In developed countries, the delivery of emergency and acute care is immediate, following an SCI. In many low-resource countries, it is rare for an individual with an acute SCI to be immobilised in the field and transported by trained personnel (Rathore et al 2008). Around the world, there is a noticeable delay between injury and presentation to the spinal unit (Burns & O'Connell 2012; Rathore et al 2008).

In South Africa, the situation is much better compared to other African countries as patients are most likely to receive proper transportation by ambulances in most South African regions (Joseph et al 2013). The public-funded healthcare system that cares for approximately 80% of South African citizens provides general care to survivors of SCIs. Rehabilitation as an integral part of healthcare services has been neglected in South Africa, with no disease-specific policy plans outlining quality indicators (Joseph 2016). However, a starting point for the discourse on rehabilitation is South Africa's own National Rehabilitation Policy that emphasises equal opportunities, the ability to participate socially, and integration back into society (Joseph et al 2013).

Irshad et al (2011) found that the main interest of most patients with a low educational level was "their ability to walk again", resulting in patients going from one place to another in search of a cure for the SCI. The cures offered and attempted by the patients in Pakistan include stem cell transplants (from China), ozone therapy, hyperbaric oxygen therapy, alternative and complementary medicine (including Ancient Greek and Arabic medicine, homoeopathy, and acupuncture), along with spiritual healing (Irshad et al 2011).

Considering all the facts discussed, the current study utilised McColl et al.'s (2001) nine indicators for successful rehabilitation and community integration combined with Maleka's (2011) study. CIMs were used to determine the level of reintegration for PLWSCI after rehabilitation.

This study found that only 37% of the respondents are fully reintegrated. The fact that moderate reintegration is just above the average (54.4%) indicates that

the existing rehabilitation is short of impact and needs to be uplifted by introducing a rehabilitation programme that could enhance reintegration. These findings are similar to that reported in other studies. Mothabeng (2007) found that the participant satisfaction with their community participation was 20%. Using multiple regressions, Mothabeng (2007) found that satisfaction with community participation accounts for 50% of the variance.

The overall low percentage of community integration in this study might be due to the absence of proper rehabilitation and poor follow-up of the patients in their communities. This finding supports the findings of Burns and O'Connell (2012) who mentioned the disparities between the developing and developed world's capacity to deliver the rehabilitation service to PLWSCI.

In this study, patients who received a home visit from a rehabilitation team were more likely to fully reintegrate into their community, in this case 75%. Of those who did not receive any home visits, only 39% managed to fully reintegrate. This result showed the contribution of the home visit factor in successful rehabilitation. The findings of the study highlighted the necessity of professionals' home visits to the patient before and after discharge. Home visits play is important in providing the bridge between the hospitalisation period and community integration (Charlifue & Gerhart 2004).

Rehabilitation services for PLWSCI should shift even more from hospital rehabilitation to the community. The goals of community integration are to restore, achieve, or maintain physical or cognitive function or occupational performance in persons with disabilities (Welage & Liu 2008). Family members and caregivers in their own environment within the community should be trained to take responsibility for the patient (Charlifue & Gerhart 2004). There are several benefits of home visits by the rehabilitation team to the patient's community. These benefits include shortening the length of hospital stay, provides service convenience to clients, promotes better therapy effectiveness, and offers greater relevance for patients to integrate back home and into the community (Welage & Liu 2008).

6.3 Physical barriers to the rehabilitation for PLWSCI in rural areas of Limpopo Province

PLWD in rural areas suffer frequently inaccessible services and infrastructure limitations (National Institute on Disability and Rehabilitation Research 2010; Trupin 2003) and have fewer advanced education supports than their counterparts without disabilities (Eldar 2001). Many people with disabilities in rural areas do not have modifications, assistive technology, or the vehicles necessary to function optimally at work and at home (Grinstein-Weiss & Curley 2003; Putnam & Tang 2005). PLWD need and want to acquire assets to facilitate increased independence (Lezzoni et al 2006). Evidence suggests that PLWD perceive healthcare, homes, and businesses as less accessible to them in rural communities than in urban settings (United States Department of Labor 2011).

PLWSCI require not only initial medical care and rehabilitation but also ongoing access to wheelchair-friendly environments and appropriate home care, equipment, transport, employment, and financial support. The management of PLWSCI, therefore, is complex, involving many healthcare professionals, organisations, and government services (Harvey 2016).

In phase 1 of this study, a comparison was made between two groups of participants. The first group comprised PLWSCI who still receive extra rehabilitation sessions at the hospital after they were discharged, while the other group comprised residents from the disability house in Polokwane. A comparison was made to discover the physical barriers of the rehabilitation for PLWSCI in rural areas of the Limpopo Province.

The results indicated no statistically significant difference in the items between the two groups ($p < 0.05$,) regarding acceptance. There was a significant difference between the two groups regarding be “able to care for your livestock”, “able to teach children home keeping tasks”, “satisfied with your ability to physically assist someone”, and “I feel like a part of this community” ($p < 0.05$).

There was no statistically significant difference in “able to move around in your home”, “able to feed yourself”, and “able to move around uneven/hill area and satisfied in your family and community” ($p > 0.05$). In this study, the participants showed satisfactory independence, orientation, and acceptance of the situation. In the sub-acute stage and before discharge from the hospital, patients should exercise all types of probable mobilisation suitable to their level of injury (Schwartz et al 2011). At the end of the sub-acute stage, the patient should be adept to functional goals such as sitting and standing and should be prepared to transfer and balance, or a wheelchair, dressing, and transfers. Initially, the goal is for successful movements. Patients who can tolerate sitting can begin to push up with static and dynamic balance training to transfer to the wheelchair and use it (Diong et al 2012). Wheelchairs, walkers and crutches are used for out of bed transferring of patients. The wheelchair is the most important tool for SCI patients to be mobile and participate in social life.

There was a significant difference between the two groups regarding satisfaction with communication with people around them, with visitors, with help or support that they received from family and friends, and with their ability to solve family and friends’ problems ($p < 0.05$). Regarding the living situation, there was a significant difference between the two groups regarding “I like where I’m living now” and “able to get to the clinic and/or hospital” ($p < 0.05$).

This result showed that PLWSCI in the disability house are more satisfied with communication than their counterparts who stay in their home community. The patient’s family support is crucial, and the family should be part of all decisions concerning patients from the early rehabilitation phases at the hospitals (Emerich et al 2012). Family support and meeting with people with the same condition should lead to a better community reintegration (Emerich et al 2012; Furlan et al 2010). The most important expectations in the chronic phase or phase to return home are ensuring the maximum independence related to the level of the patient’s injury, integration of the patient to society, and teaching the importance of the family’s role (Baslo 2013). In addition, house modifications

are important for patients with SCI to have independent activities of daily living. Adequate insulation must be provided at home (Baslo 2013).

Results regarding productivity showed no significant association in “able to collect at a communal water tap”, “able to wash dishes, clothes, etc.”, “able to cook a meal for your family”, and “able to work in your garden/yard/field” ($p > 0.05$), while “I’ve something to do in the community” shows a significant difference between the two groups ($p < 0.05$). The participants from the disability house are more productive than other participants.

There was no statistically significant association between “spending leisure time and to have fun in spare free time”, “able to do an activity for self-enjoyment or relaxation”, “able to go shopping in town”, and “able to do any physical activity such as playing any sport” between the two groups ($p > 0.05$). However, the mean score of participants from Centenary House was significantly higher than the counterpart regarding “able to go out with friends or watch a soccer match at the stadium”.

One of the important features of this period is restoring the patient’s psychological and emotional state because of the high incidence of depression in patients during the first six months (about one out of three patients) (Lee & Mittelstaedt 2004). Depression is not a natural process experienced after SCI but a complication that needs to be treated. The rehabilitation team should find the patient’s role in society. Successful rehabilitation allows SCI patients to be more social, to use their own functions and skills for creative jobs, and to deal with psychological and physical problems (Petrova et al 2015).

6.4 The designed rehabilitation programme

Acknowledging the absence of sufficient specialised rehabilitation centres and the seriousness of the implications thereof, this study’s aim was to design an effective rehabilitation programme to enhance proper community reintegration, and it should be the priority of everyone in the rehabilitation field and

community. A participant (SCI patient) identified one of the challenges pertaining to SCI patients:

"Like marriage, a very small number of people accept to marry a person with spinal cord injuries, unless if [the] spinal cord injury person can marry [an] other spinal cord injury person. I have seen a lot of women – after injury, they lose their men. [I] didn't know what those men think whether this woman is no more useful or what, but it gives me a lot of pain when I see this situation."

An effective intervention should be a multi-component strategy that emphasises and encompasses a multidisciplinary team with a clear distribution of power, documentation, a home programme, secure mobility and assistive devices, indicators for successful rehabilitation, and specific tasks for the sub-acute or transitional phase before discharge from the hospital. Evidence suggests that a rehabilitation programme that accommodates a multidisciplinary team with clear tasks and goals is more likely to lead to successful rehabilitation and community integration (Maleka 2011). For an intervention programme to be effective, a clear understanding of the influence of the variables is needed (Castro, Barrera & Holleran Steiker 2010). Seven variables formed the rehabilitation programme designed in this study: 1) formation of the rehabilitation programme, 2) distribution of power, 3) documentation, 4) mobility and assistive devices, 5) home programme, 6) sub-acute phase tasks, and 7) outcome of successful revalidation.

6.4.1 Formation of a rehabilitation programme

The literature recommended a team approach to SCI rehabilitation (Maleka 2011; Mothabeng 2007). Such a multidisciplinary team in the rehabilitation of SCI patients should include different professionals from healthcare and social sectors (Petrova et al 2015).

During phase 1 of this study, it was evident that there was no rehabilitation team in the Limpopo Province specifically for SCI. Participants (healthcare professionals) mentioned the need for a spinal unit as well as a rehabilitation programme and rehabilitation team.

"In this hospital, we don't surgically operate spinal cord injury patients that is why we don't have a proper rehabilitation programme for the spinal cord injuries patients. Also, the hospital didn't manage the programme of the rehabilitation according to the protocol supposed to be, for instance we start the rehabilitation for the spinal cord injury patients after six weeks while according to the programme, which is known to all the practitioners, we [are] supposed to start within three days after the operation day."

The views of the practitioners and patients, together with the evidence gained from an in-depth literature review was presented to experts in the Delphi study to reach a consensus on the formation of the rehabilitation team as well as who should be included in the team, why they should be included, and what tasks should be done. A consensus was reached by the experts regarding the formation of the team. A multidisciplinary approach was recommended for this programme.

6.4.2 Distribution of power

Adherence to the treatment protocol and the presence of guidelines are the core and basic management of patients in the medical field. Sackett et al (2000) delineate two distinct components of guidelines for clinical practice, namely the summary of the evidence upon which the guidelines are based and the detailed instructions or recommendations for applying that evidence to our patients.

The rehabilitation approach must start as early as possible by at least forming the baseline for the treatment of the patient. Nas et al (2015) state that SCI leads to serious disability and complications. The treatment and rehabilitation process of SCI is long, expensive, and requires a multidisciplinary approach. Early rehabilitation is important to prevent disability and complications (Emerich et al 2012).

Healthcare professionals in the Limpopo Province complained about the absence of the protocol. In phase 1 it was discovered that the absence of a rehabilitation protocol in the province led to a mix of the powers and responsibilities of different role-players. According to a physiotherapist:

"We need to have a separated spinal unit so that we can adhere to the protocol that guides the care of such patients. It should be separated from the orthopaedic unit. Really, there are a lot of complications of those patients starting from the bedsores, prolonged urine catheter, kidney problems, sudden rise of temperature, chest complications, and other problems which need consultation from other doctors and other specialisation interference."

Experts also reached a consensus regarding the distribution of power and responsibilities among the team members. Six points in the programme highlight the distribution of powers; these factors will be discussed in the sections that follow.

6.4.3 Documentation

An effective referral system ensures a close relationship between all levels of the health system and ensures that people receive the best possible care closest to home (WHO 2017). An effective referral system can ensure that clients receive optimal care, hospital facilities are used optimally and cost-effectively, and clients who need specialist services the most can access them timely.

A referral system will function effectively if all service providers are expected to adhere to the referral discipline, to refer appropriately, and to follow the agreed protocols of care (where this system applies) (Department of Health 2003). During phase 1 of this study, participants (healthcare professionals) mentioned the lack of a referral system between the multidisciplinary team members and the professionals in the same field. One healthcare professional stated:

"All in-hospital patients receive services from all disciplines individually. Like each professional gives his service regardless of other professionals' programmes. Some allied services in other wards (not the orthopaedic ward), they work with [a] referral system like they see the patient if the patients are referred to them; otherwise, patients will be referred to their origin or nearest hospital to receive the service."

In South Africa, the quality in healthcare can be based on the quality of professional training and education including ethical, legal, and professionalism (Muller 1996). The regulatory bodies, such as the Health Professional Council South Africa (HPCSA) has been regulating the standard of healthcare practice in South Africa. Practitioners should follow the ethical and legal guidelines of the HPCSA, which clearly indicate the importance of documentation and the correct referral among practitioners.

All the information was presented to the experts participating in the Delphi study. The professionals' ideas and PLWSCI were also presented to the experts. The experts reached consensus regarding documentation and referral guidelines regarding the management of SCI patients. Although they could not reach consensus regarding the medico-legal document to be included in the referral document, they established a framework for the items that should be included in the referral document.

6.4.4 Assistive device

Equipment for PLWSCI needs to be practical, durable, and repairable. It would be ideal if the patient or his/her family could repair their equipment. In case the patient or his/her family were not able to repair the equipment, they should have access to someone who can assist them in repairing the equipment. The availability of equipment and mobility devices for SCI patients will contribute to their successful integration into the community (Weerts & Wyndaele 2011).

Healthcare practitioners and the rehabilitation team indicated that the lack of material and human resources is problematic during the provision of care to patients. Practitioners identified bracing, wheelchairs, commodes, and crutches as the main challenged resources when it comes to SCI patients' rehabilitation. An occupational therapist opined: "*I think one of our biggest challenges is lack of resources like of bracing, wheelchairs, commodes, and sometimes crutches as they sometimes are delayed from the suppliers".*

A physiotherapist added*: "Actually, I want to add to my colleague that also repairing of the equipment sometimes are affecting the mobility of the patient and as well affecting their community integration in [a] later stage".*

Experts reached a consensus regarding the distribution and availability of assistive devices to PLWSCI. They recommended that assistive devices should be accessible to all patients. They identified five points to regulate the distribution and availability of assistive devices.

6.4.5 Sub-acute stage: rehabilitation of sub-acute stage of SCI

The sub-acute stage of the rehabilitation process is where all the rehabilitation team members must engage with the patient to be prepared to discharge from the hospital (Diong et al 2012; Nas et al 2015; Schwartz et al 2011). FGD participants also raised the issue of the absence of discharge criteria for the patients with SCIs. One of the occupational therapists said:

"The problem is the patients sometimes get discharged without consulting or informing us as professionals about if this patient is ready for discharge or not. The doctors when they decide to discharge the patients, they don't arrange with us the discharge date …"

At the end of the sub-acute stage, the patient should be adept to sit and stand and are prepared to transfer and balance (Schwartz et al 2011). Diong et al (2012) reported that in the sub-acute stage, patients usually presented with orthostatic hypotension or syncope while sitting or standing. The purpose of rehabilitation in this stage is to focus on stability and strength education for sitting and transportation. Functional goals must prepare the SCI patient for movements (Schwartz et al 2011).

Experts were not able to reach a consensus regarding the duration of the sub-acute phase of rehabilitation of SCI patients before being discharged to go home. Although they could identify the tasks to be done during this period, they leave the duration to be determined according to the type of injury, healing speed, and the age and muscle strength of the patient.

6.4.6 Home programme

This study revealed that healthcare professionals who deal with SCIs do not have an outreach programme to visit the patients at their homes. A physiotherapist stated*: "… I don't remember when last I went for [a] home visit officially from this department … (Aaa) … I used to visit my patient at home, but that is privately."*

The home programme is important to ensure the successful reintegration of the patient. It was confirmed in phase 1 of this study that the patients who receive home visits are more likely to reintegrate successfully than their counterparts who did not receive home visits do.

Following the patient condition, psychological support, home modification follow-up, and evaluation of the functional goals are the most important parts of the home visit as part of the home programme (Baslo 2013). The FGD also pointed out the psychological and social implications of SCIs that can be solved by the home visits. A social worker said:

"Regarding the acceptance of the situation either by the patient or the community, by the way this matter is having bilateral ends, like I mean the acceptance by the patient himself and the acceptance of the community to the patient, and here the role of the local social worker and psychologist and all other therapists during the rehabilitation period. Lack of acceptance of the condition required presence of psychologist and social worker within the rehabilitation team to overcome this matter; besides, other practitioners must also help toward overcoming the physical and psychological impairments."

Experts in the Delphi study recommended guidelines of the home programme and steps to follow in the process implementing a home programme. Experts highlighted the home visit as part of the home programme. Evaluation of the home programme and assessment of the patient condition after discharge is a crucial part of this programme (House et al 2009).

6.4.7 Outcome of the successful rehabilitation programme

A programme should have outcome measures or indicators for success (Alexander et al 2009). Programme personnel should ask what results are expected from each output to develop outcomes. Outcomes should be something that the project wants to maximise or improve (Tsai & Wadden 2009). A multi-component programme that is delivered through multidisciplinary care could be more effective than a programme delivered by individual healthcare professionals (Tsai & Wadden 2009). The most important outcome of successful rehabilitation is to ensure maximum independence related to the level of the patient's injury (Baslo 2013).

Experts described clinical indicators to measure the success of the rehabilitation journey for each patient according to his/her level of injury. These clinical indicators include psychological, social, and physical indicators.

6.5 The rehabilitation programme

Formation of the rehabilitation team

Items

- The rehabilitation team should include a rehabilitation doctor, rehabilitation professional nurse, physiotherapist, occupational therapist, dietician, psychologist, social worker, orthotist, speech therapist, caregiver, religious group (for spiritual support), and family members.
- A multidisciplinary approach will enhance the holistic management and speedy recovery.

1. Distribution of powers

Items

- The rehabilitation process in the acute phase must start immediately after stabilising the patient's medical condition.
- In all phases of rehabilitation, a team co-plan is important for the

rehabilitation of SCI patients.

- The long-term goals of the rehabilitation must be to reach perfect community integration.
- Handover must be done professionally through referral letters. Referral letters must include summary notes about the patient's functional level and/or achievements.
- A team co-plan is important for the rehabilitation of SCI patients.

2. Documentation

Items

- Documentation must include the patient's details, present and past medical history, socioeconomic history, investigations and tests done, assessments, findings and diagnosis, management done, medications, and further plans, as well as details of rehabilitation done by each therapist.

A copy of the reference letters between the practitioners must be kept in the patient file.

3. Mobility and assistive devices

Items

- To secure wheelchairs and walking assistive devices, all patients should be within the medical aid umbrella. Disability organisations should share responsibilities and the RAF should share the responsibility of the availability of wheelchairs for people with SCIs due to road accidents.
- Wheelchairs must be accessible to all patients.
- Wheelchairs accessories should include hand protection, tyre, mitts, gloves sponge, and matt to prevent skin sores.
- When providing patients with devices (such as a wheelchair), rural

settings must be considered. The patient must be able to manoeuvre the device in all types of environments.

4. Sub-acute or transitional phase

Items

- The duration of the sub-acute phase of rehabilitation depends on (i) speed of recovery, (ii) response of the patient to treatment, (iii) the age of the patient, (iv) patient's lifestyle before the injury, and (v) injury location and type.
- The patient must be willing to spend the necessary time during the rehabilitation programme to gain the required strength and train new functional activities.
- During the sub-acute phase of rehabilitation, the caregiver and community nurse should be trained to monitor the home programme.
- During the sub-acute phase, the rehabilitation team will work on gaiting around, bathing, dressing, skincare, diet and feeding himself/herself, and bowel and bladder management.
- At the end of the sub-acute phase, the patient should be able to transfer from the bed to the wheelchair and back to the bed as well as pressure relief.
- At the end of the sub-acute phase, the patient must use his/her assistive device whether its wheelchair, callipers, or crutches for all types of environments.

5. Home programme

Items

- A written home programme should be incorporated during the rehabilitation of the patient before discharge.
- The home programme must be clear and include the type, frequency, and safety.
- The multidisciplinary team must compile the programme as a team.

- The caregiver and community nurse should monitor the programme homework.
- Home visits from the professionals are important to evaluate the home programme.
- A planned programme with clear goals and collective work of the rehabilitation team should protect the patients from becoming over-exercised or under-exercised.
- Patients should be introduced to the community by the whole team, not only by the psychologist or social workers.

6. Outcome of successful rehabilitation

Indicators

- The patient should be as functionally independent as possible in all the self-care areas allowed by existing muscle functions appropriate for his/her level and severity of injury.
- The patient must have orthopaedic clearance for gait training. The patient's skin should be free of bedsores.
- Patients should express and understand the limitations of gaiting and should have realistic expectations.
- On discharge, paraplegic patients should be able to wash, dress, feed themselves, pad, do a skin check, as well as ambulation using the prescribed assistive device.
- On discharge tetraplegic patients (depending on the level of injury) should be able to wash, feed, dress, and pad themselves and have wheelchair/electric wheelchair mobility.
- The rehabilitation team should monitor the patient's reintegration into the community as a team.

6.6 Conclusion

Rehabilitation is the bridge between the SCI and successful community integration. A comprehensive, rehabilitation programme implemented by a multidisciplinary team should enhance the successful reintegration of PLWSCI.

The findings of the study revealed that a lack of rehabilitation centres and programmes results in many challenges. Some of these challenges affect the healthcare professionals directly and patients indirectly. The challenges that affect professionals directly include:

1) Unidentified period to start with rehabilitation of SCI patients
2) The importance of additional human and enough material resources.
3) The importance of full assessment of the patients by different healthcare professionals.
4) A need for training courses for management.
5) Treatment and care for patients with SCIs.
6) A need for a special unit with specialist and community rehabilitation centres.
7) Besides the impact of these challenges, there are other challenges which impact the patients directly including:
    - The importance of home visits; absence of a clear rehabilitation programme and protocol
    - Poor follow-up of these patients returned to their communities

All of these challenges impact directly on a poor community reintegration for PLWSCI in Limpopo. Although several studies have been done to highlight the rehabilitation and community reintegration challenges in rural areas, no studies have been done to design a rehabilitation programme based on the views of the patients and the professionals in Limpopo Province to enhance the community integration for PLWSCI in Limpopo.

The programme designed in this study should thus be used as a tool to rehabilitate PLWSCI in the Limpopo Province. It allows for the implementation in

regions where there is an absence of specialised rehabilitation centres for people with SCIs in rural settings. Identification of the sub-acute phase tasks, home programme elements, and outcome indicators of successful rehabilitation can assist in enhancing successful community reintegration for PLWSCI.

6.7 Recommendations

The following recommendations are made based on the outcome of this study for successful rehabilitation and community reintegration for PLWSCI in rural areas of the Limpopo Province, South Africa.

Provincial authority

- There is an urgent need for a rehabilitation centre for SCI patients in the province.
- Allowance for training and workshops for allied health professionals, nurses, and rehabilitation doctors should be put in place.
- Safety, security, and accessibility of public facilities should be addressed to assist PLWSCI to reintegrate and be effective citizens in this province.
- A rehabilitation programme for PLWD such as the one in this study should be given increased attention.
- In addition, health promotion programmes should also aim to enhance community reintegration for PLWSCI.

Healthcare facilities

- Separate unit for patients with spinal cord injuries;
- Well trained staff to deal with SCI;
- Formation of a rehabilitation team in each hospital; and
- Enhance practitioners' nurses and workers to attend workshops and courses.

Research

- Implementation of the designed interventions to test the effectiveness thereof in both urban and rural settings
- Researchers should take an active leadership role to ensure objective and valid conduct of intervention studies.
- Identification and development of appropriate clinical tools and valid measures that are specific to relevant therapeutic targets

6.8 Limitations

There are additional issues that deserve attention to improve tools and knowledge affecting the management of SCI. These issues are summarised as follows:

- Limited ability to address true quality of life for PLWSCI socially and economically;
- Measurements of other important aspects of function, including the interplay between spasticity, pain, and motor and sensory functions are at an even earlier stage of rehabilitation; and
- There are concerns regarding the potential for any treatment to produce heightened neuropathic pain.

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APPENDICES

Appendix 1: TREC clearance certificate

University of Limpopo
Department of Research Administration and Development
Private Bag X1106, Sovenga, 0727, South Africa
Tel: (015) 268 2212, Fax: (015) 268 2306, Email:noko.monene@ul.ac.za

TURFLOOP RESEARCH ETHICS COMMITTEE CLEARANCE CERTIFICATE

MEETING:	**05 November 2015**
PROJECT NUMBER:	**TREC/212/2015: PG**
PROJECT:	
Title:	Rehabilitation program to enhance community reintegration for People living with spinal cord injuries in rural areas of Limpopo Province-South Africa
Researchers:	Mr EE Mohamed
Supervisor:	Prof NP Mbambo-Kekana
Co-Supervisor:	Prof L Skaal
Department:	Nursing Science
School:	Health Care Sciences
Degree:	PhD in Health Sciences

PROF TAB MASHEGO
CHAIRPERSON: TURFLOOP RESEARCH ETHICS COMMITTEE

The Turfloop Research Ethics Committee (TREC) is registered with the National Health Research Ethics Council, Registration Number: **REC-0310111-031**

Note:
i) **Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.**
ii) **The budget for the research will be considered separately from the protocol.**
PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.

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Appendix 2: Budget

This research will be Self-financed by the researcher

No	Item	Description/Justification	Amount (R)
1.	Data Collection	Data collection logistics	25 000
2.	Data Processing	Transcription and Translation	12 000
3.	Editing	Person qualified as a language and content editor	10 000
4.	Binding	Binding of 5 copies	2 500
5.	Copies	All the copies that will be needed including the draft work	2 500
6.	Analysis	Statistician will assist with analysis	7 000
7.	University registration	University registration for three years	75 000
TOTAL AMOUNT			134 000

Appendix 3A: Qualitative question

Information box:

Thank you for agreeing to participate in this study.

My name is Ehab Elsayed Mohamed-----

I am a researcher from the University of Limpopo

The aim of the study is to devolve this a rehabilitation programme to enhance community

Reintegration for people living with spinal cord

Injuries in the rural area of Limpopo Province

South Africa.

The study is non-invasive, and only focus group interviews and questionnaires will be used to

collect data

Participation in this Study is completely voluntary

and that you may withdraw from it at any time and

without supplying reasons.

This will have no influence on the regular treatment

that holds for my condition neither will it influence the care that I receive from my regular doctor.

You will be asked to sign a consent form before participating in the study.

Should you have any queries, kindly contact:

E E Mohamed (0726918815)

Appendix 3B: English consent form

Statement concerning participation in a Clinical Research

Name of Research

Rehabilitation Programme to enhance community reintegration for People living with Spinal cord injuries in rural areas of Limpopo Province-South Africa

I have read the information on */heard the aims and objectives of the proposed study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurized to participate in any way.

I know that photographs/electronic images/sound recordings will be taken of me. I am aware that this material may be used in scientific publications which will be electronically available throughout the world. I consent to this provided that my name/and hospital number* is/are* not revealed. Regarding images of the face, I understand that it may not be possible to disguise my identity, and I consent to the use of these images

I understand that participation in this Study is completely voluntary and that I may withdraw from it at any time and without supplying reasons. This will have no influence on the regular treatment that holds for my condition neither will it influence the care that I receive from my regular doctor.

I know that this study has been approved by the Turfloop Research Ethics Committee (TREC), University of Limpopo. I am fully aware that the results of this Study will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

I hereby give consent to participate in this Study.

_____ _____

Name of patient/volunteer Signature of patient

Place: _____

Date: _____

Witness

_____

Statement by the Researcher

I provided verbal and/or written* information regarding this Trial/Study/Project*

I agree to answer any future questions concerning Study as best as I am able.

I will adhere to the approved protocol.

Name of Researcher _____

Signature _____

Date _____

Place _____

Appendix 4: Department of health permission to conduct the study

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Latif Shamila Ref:4/2/2

Mohammed EE
University of Limpopo

Greetings,

RE: Rehabilitation program to enhance community reintegration for people living with spinal cord injuries in rural areas of Limpopo.

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
   - Research must be loaded on the NHRD site (http://nhrd.hst.org.za) by the researcher.
   - Further arrangement should be made with the targeted institutions, after consultation with the District Executive Manager.
   - In the course of your study there should be no action that disrupts the services.
   - After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
   - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
   - The above approval is valid for a 3 year period.
   - If the proposal has been amended, a new approval should be sought from the Department of Health.
   - Kindly note, that the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated.

Head of Department Date 18/02/16

18 College Street, Polokwane, 0700, Private Bag x9302, POLOLKWANE, 0700
Tel: (015) 293 6000, Fax: (015) 293 6211/20 Website: http/www.limpopo.gov.za

Appendix 5: Spinal cord injury integration measure

According to McColl et al (2001), community integration should consist of nine indicators: orientation, acceptance, and conformity, close and diffuse relationships, living situation, independence, productivity, and leisure

Maleka 2011 developed a measure for stroke community integration in Limpopo Province.

Using both models (Maleka 2011; McColl et al., 2001), this research developed a measure to scale the community integration for PLWSCI in a rural area of Limpopo.

The measure uses four (4) point scale as follows:

No (0)	Rarely Happen (1)	Sometimes (2)	Always Happen (3)

Total scoring is 44 x 3 = 132, patient score = the total score / 132 x 100%

Interpret and provide feedback for the patient by placing the patient's score on the scale below.

Cut off points:

80% and above means full reintegration

79%-60% moderate reintegration

59%-41% minimal reintegration

40%-0% no reintegration

Section A: Demographic Data of the participant

Patient Name: _____

Surname: _____

Age: _____ Race: _____ Gender: _____

Years of formal education obtained: _____

Current employment status: _____

Current / previous occupation: _____

Marital status: _____ Dependants Numbers: _____

Date of injury: _____

Type of physical weakness (paraplegic/tetraplegic/monoplegic): _____

Grants: _____

Date of interview: _____ Location: _____

Who was interviewed/assessed (patient and/or caregiver): _____

Patient's physical address & contact number:

_____

_____

How long the patient had been living in this community before and after injury:

_____

Name of the interviewer: _____

Baseline and follow-up assessment score: _____

Section B: Orientation, work & education

1.	Are you able to make decisions regarding your life and family needs?	NO (0)	Rarely Happen (1)	Sometimes (2)	Always Happen (3)
2.	Are you able to remember things told and events easily?				
3.	Are you able get up and out of bed in the morning?				
4.	Are you able to wash yourself?				
5.	Are you able to dress yourself?				

Section C: Acceptance

1	I feel that I am accepted in this community	NO (0)	Rarely Happen (1)	Sometimes (2)	Always Happen (3)
2	Are you able to attend social events in your community such as funerals, parties, and weddings?				
3	Are you able to attend community structures meetings or meeting called by the chief/councillor in your community?				
4	How Satisfied are you with your appearance in the public?				

Section D: Conformity

1	Are you able to care your Livestock (feed your animal if you have)?	NO (0)	Rarely Happen (1)	Sometimes (2	Always Happen (3)
2	Are you able to teach children home keeping tasks, e.g. cultural/traditional behaviours, cooking, milking the cow, etc.?				
3	Are you able to use the same transport you used before the injury?				
4	How are you satisfied with your ability to physically assist someone?				
5.	I feel like part of this community, like I belong here				

Section E: Close and diffuse relationships

1	How satisfied are you with your interaction with other people?	NO (0)	Rarely Happen (1)	Sometimes (2	Always Happen (3)
2	Are you able to carry out your community role, e.g. singing in the choir, helping at the local school, community leadership, or burying your congregates?				
3	How satisfied are you with your communication with people around you?				
4	How satisfied are you with your visitors?				

5	How satisfied are you with your help and support that you receive from your family and friends?				
6	How satisfied are you with your ability to solve family and friends' problems?				

Section F: Living situation

1	I like where I'm living now	NO (0)	Rarely Happen (1)	Sometimes (2)	Always Happen (3)
2	I can be independent in this community				
3	Are you able to go back to work (paid or volunteer) / school or college?				
4	Are you able to attend school or training programs in or out of your community?				
5	Are you able to get to the clinic / hospital to collect your medication or for rehabilitation / nursing /				

	medical help?				

Section G: Independence

1	Are you able to move around in your home?	NO (0)	Rarely Happen (1)	Sometimes (2)	Always Happen (3)
2	Are you able to feed your self?				
3	Are you able to move around in your community?				
4	Are you able to move around uneven/a hill area?				
5	Are you satisfied in your family and community?				

Section H: Productivity

1.	I have something to do in this community during that main part of my day that is useful and productive	NO (0)	Rarely Happen (1)	Sometimes (2)	Always Happen (3)
2	Are you able to collect water from the river/communal tap?				
3	Are you able to wash dishes, clothes& and clean the area around you?				
4	Are you able to cook a meal for your family?				
5	Are you able to work in your garden, yard or field?				

Section I: Leisure

1.	There are things that I can do in this community for fun in my free time	NO (0)	Rarely Happen (1)	Sometimes (2)	Always /Agree (3)
2.	Are you able to do an activity for self-enjoyment or relaxation such as to listen to radio or watch TV or read book/bible/newspaper?				
3	Are you able to go shopping in town?				
4	Are you able to go out with friends or watch a soccer match at a stadium?				
5	Are you able to do any physical activity such as plying any sport?				

Section J: Rehabilitation

1.	The rehabilitation period was enough to promote my reintegration into this community	NO (0)	Rarely Happen (1)	Sometimes (2)	Always /Agree (3)
2.	I received a home visit from the rehabilitation team regularly (assessor must explain what is the rehab team)				
3.	During my admission at the hospital all the rehabilitation team visited me (assessor must explain this question)				
4.	During my admission at the hospital, the rehabilitation team were following my condition until discharge (assessor must explain this question)				

Appendix 6: Translation of Qualitative question, and the questionnaire dinyakisiso:

Dipotsiso tseo di tlago butsiswa mo makgotleng

“Hlalosa dihlotlo tseo batho ba kgobalo ya mokokotlo ba lebanego le tsona bakeng sa go phela di naga magaeng mo tulong ya provensing ya limpopo”.

Dipotsiso

Palo ya kgobalo ya mokoktlo go boela sechabeng.

Palo (0)	E direga ga mmalwa (1)	E direga ka nako tse dingwe (2)	E direga ka mehla ()

Dipalo ka mokage di kopantswe (44 x 3) di lekanale 132,

dipalo tsa balwetsi di lekana le dipalo ka maka e di kopantswe /132 x 100%

Hlalosha obe ofeditshwaelotsabalwetsi ka go fa dipalo o shomishatekanyo ye e latelago:

80% le go feta e bontsha go bushetswasechabenggo gofeleletsego

79% go fihla 60% e bontsha go busetswasetshabeng mo gokgotsofatsago

59% go fihla 41% e boncha go busetswasetshabeng go sakgotsofatsago

40% go fihla 0% ga gona pusetso setshabeng

Seripa A: Demographic Data of the participant:

Tshedimosho ya motsea-karolo

Leina: ---------- Sefane: ----------

Mengwaga: ---------- Mohlobo: ---------- Bong:----------

Mengwaga ya thuto ya semolao---------- o soma eng----------

Moshomo wa bjale/pele ----------

Go nyalwa/nyalwa ----------

Palo ya batho ba o ba itshetlegileng wena ----------

letsatsi la kgobalo ----------

Mohuta wa kgobalo(Paraglegic/tetraplegic/Monoplegic ----------

Mphiwafela ----------

Letsatsi la poledishano ---------- Lefelo ----------

Ke ofe wo a bego a dira dipoledishano (molwetsi/mohlokomedi wa molwetsi)

----

ya molwetsi mo a dulang gona le nomoro ya mogala ----------

Ke nako ye kaakang molwetsi a phela sechabengo a lego go sona se pele le morago ga kgobalo----------
----

Leina la motho wa botsitsa ----------Tekolo ya mathomo le yeo e latelgo----------

Seripa B: Tlwaetso, moshomo le Thuto

1.	O kgona go tsea sephetho mabapi le dinyakwa tsa gago tsa bophelo le tsa lapa	Palo (0)	Edirega ga mmalwa(1)	E direga ka nako tse dingwe(2)	E direga ka mehla(3)
2.	O kgona go gopola dilo tseo o boditswego tsona le dilo tseo di diregago letsatsing leo				
3.	O kgona go ema le go tsoga marobalong mesong				
4.	o kgona go ihlapisha				
5.	O kgona go ikapesha				

Seripa C: Kamogelo

1	Ke kwa ke amogelegile Setshabeng	Palo (0)	Edirega ga mmalwa(1)	E direga ka nako tse dingwe(2)	E direga ka mehla(3)
2	o kgona go ya ditiragalong tsa setshaba go swana le mahung,meletlong le manyalong				
3	o kgona go ya dikopanong tsa sechaba tseo di biditswego ke kgoshi/ntona goba mokhanselara				
4	O kgotsofala ga kaakang ka go bonagala ga gago sechabeng				

Seripa D: Tumello

1	O kgona go hlokomela leruo la gago (ge onale lona)	Palo (0)	Edirega ga mmalwa(1)	E direga ka nako tse dingwe(2)	E direga ka mehla(3)
2	O kgona go ruta bana meshomo ya ka gae go swana le mekgwa, le maitshwaro a setso,go apea, go gama dikgomo				
3	O kgona go shomisha dinamelwa go swana le pele ga kgobalo				
4	O kgotsofala ga kaakang le go kgona ga gago go thusha motho e mongwe				
5.	Ke kwa ke le leloko la sechaba, ke ikwa				

	ke le gae				

Seripa E: Go kgona go fedisha dikamano

1	Wa kgotsofala ka kamano ya gago le batho ba bangwe	Palo (0)	Edirega ga mmalwa(1)	E direga ka nako tse dingwe(2)	E direga ka mehla(3)
2	O kgona go tsea karolo mo ditiragalong tsa sechaba… go swana le go opela, go thusha sekolong sa selegae, polokong ya batho ba o o tsenang le bona kereke				
3	O kgotsofala ga kaakang mabapi le go bolela le batho ba o phelang le bona				
4	O kgotsofala ka baeng bao ba go etelang				
5	Wa kgotsofala ka thusho le thekgo yeo o e				

	humanago go tswa go ba lelapa le bagwera				
6	Wa kgotsofala ka go kgona ga gago go rarolla mathata a lapa le bao le go bagwera ba gagao				

Seripa F: Seemo sa moo ke phelago gona

1	ke dulago ga bjale	Palo (0)	Edirega ga mmalwa(1)	E direga ka nako tse dingwe(2)	E direga ka mehla(3)
2	Nka phela ka bonna sechabeng				
3	o a kgona go boela moshomong(o patelwa goba o ithaopa)/goba sekolong				
4	o kgona go ya sekolong goba mananeo a mangwe a thuto secchabeng				
5	O kgona go ya kliniking /sepetlela go tsea dihlare goba go				

	kgona go ya tsosholoshong ya dikgobalo				

Seripa G: Go itirela

1	o kgona go sepela-sepela ka gae	Palo (0)	Edirega ga mmalwa(1)	E direga ka nako tse dingwe(2)	E direga Ka mehla(3)
2	o kgona go itesha dijo				
3	O kgona go sepela sepela mo sechabeng				
4	O kgona go sepela mo mafelong a dithaba le diolo				
5	Wa kgotsofala ka bophelo ba ka lapeng le ba mo sechabeng				

Seripa H: Go tsweletsa

1.	Kena le seo nkase dirago mo sechabeng ka nako ya bohlokwa mo letsatsing laka	Palo (0)	Edirega ga mmalwa(1)	E direga ka nako tse dingwe(2)	E direga ka mehla(3)
2	O kgona go kga meetsi di nokeng goba mo pomping ya sechaba				
3	O kgona go hlatswa dibjana, diaparo le hlwekisa moo o dulang gona				
4	O kgona go apeela le lapa la gago dijo				
5	O kgona go shoma ka serapeng sa merogo goba masemong				

Seripa I: Leisure

1.	Gona le dilo tso nka di dirang go ithabisha ka nako yaka yeo ke sa direго selo	Palo (0)	Edirega ga mmalwa (1)	E direga ka nako tse dingwe(2)	E direga ka mehla(3)
2.	o kgona go dira dilo tsa go ithabisha go swana le go bogela Tv goba go bala puka, Bible goba kuranta				
3	O kgona go ya go reka dilo ka toropong				
4	O kgona go tswa go bogela dipapadi le bagwera ko Stadium.				
5	O kgona go dira dilo tsa mmele go swana le go raloka dipapadi				

Seripa J: Rehabilitation

1.	Nako ya tsosholoshao/pholo yeo e lekaneng gore ke kgone boela sechabeng	Palo (0)	Edirega ga mmalwa(1)	E direga ka nako tse dingwe(2)	E direga ka mehla(3)
2.	Ke amogela ketelo ya gae go tswa go sehlopha sa tsosholosho/Phodisho				
3.	Ka nako yeo ke amogelwa sepetlela, sehlopha sa Tsosholosho/Phodisho se ile sa nketela(Mohlahlobi swanetse a hlalose potsisho ye)				
4.	Ka nako ye ke amogelwa sepetlela, sehlopha sa tsosholsho/phodisho se ile sa shala morago seemo saka go				

	fihlela ke etswa sepetlela				

Appendix 7: Delphi Study Round 1

Rehabilitation Programme

Below is the suggestion of the rehabilitation programme components.

These suggestions came from:

- Patients who are post spinal cord injuries.
- Professionals, who are part of the multidisciplinary team, deal with SCIs rehabilitation in Limpopo.

To complete this programme to suit PLWSCIs in the rural area of Limpopo we need your feedback in this round 1 of the Delphi study.

Section 1 Structure

Assembly Team

In your opinion, who should be involved in the rehabilitation and management of the SCI patients?
Please tick as many as you want

Profession	Tick X
Physiotherapist	
Occupational therapist	
Dietician	
Social workers	
Psychologist	
Others, Specify----------	

Explain reasons for your choice----------

In your Opinion, do you think community nurses should form part of the rehabilitation team?

Yes	No

If yes, explain what role they will play in rehabilitation of the patients
---

If No, Why not: ----------

In your Opinion, do you think Caregivers/CBRW should form part of the rehabilitation team?

If yes, explain what role they will play in rehabilitation of the patients
---

If No, Why not:----------

In your Opinion, do you think family of the Patient should form part of the rehabilitation team?

If yes, explain what role they will play in rehabilitation of the patients:

If No, Why not: ----------

At what stage of rehabilitation should family members be involved? Motivate: ----------
---

In your Opinion, do you think Religious group should form part of the rehabilitation team?

If yes, explain what role they will play in rehabilitation of the patients

---

If No, Why not: ----------

In your Opinion, do you think Community members should form part of the rehabilitation team?

If yes, explain what role they will play in rehabilitation of the patients:

If No, Why not:----------

Rehabilitation Team – Distribution of powers

In your opinion when should rehabilitation for people with spinal cord injury (PLWSCI) start: state reasons ----------

---

-

In your Opinion which rehabilitation profession should first see the SCI patient?

Elaborate: ----------

Do you currently co-plan of the programme or co-treat a patient with other members of the rehabilitation team?

Remarks: ----------

In your opinion is it necessary to co-plan the rehabilitation of SCI patient as a team?

Elaborate: ----------

Do you sometimes do activity that is not in your scope of practice?

Elaborate: ----------

Hand over must happen between the practitioners in the same profession.

Agree	Not agree

Suggestions ----------

Handover system or referral must include summary notes about the patient functional level

Agree	Not agree

Documentation

What do you understand about documentation?----------

Hospital settings

What do you think about the decentralization of the patients care?
(The dispersion or distribution of functions and powers, the delegation of power from a central authority to regional and local authorities. In the case of rehabilitation in rural areas, the redistribution of function from urban centres to outlying areas) (Saltman, Bankauskaite & Vrangbæk 2007).

Section 2 process

Mobility and assistive devices

When giving a patient's devices, e.g. wheelchair, we must consider rural area setting

Agree	Not Agree

Remarks: ----------

Wheelchair accessories should include Hand protectors, wheelie mitts, and gloves sponge matt to prevents skin sore.

Agree	Not Agree

Suggestions for devices and Accessories for both paraplegia and tetraplegia ----
---

Are wheelchairs easily accessible to SCI patients?
If not, what process can you suggest to facilitate easy access?

Are wheelchair accessories easily accessible to patients?
If not, what are the challenges that hinder this access and how can this access be improved? ----------
---

Home Programme

Home programme must be clear and including the type and the frequency and safety

Agree	Not Agree

Do you think a written home programme should be incorporated in the rehabilitation of patients?

Agree	Not Agree

Why/ why not----------

Who should compile a home programme book? ----------

Who should monitor if the homework is executed? ----------

Home visit is important to evaluate the home setting, to follow up the home programme

Agree	Not Agree

Introduction to the community must be done by psychologist and social worker?

Agree	Not Agree

Suggestions----------

How long should be the duration of the rehabilitation? ----------

Elaborate----------

How can we control the intensity of the programme? And how can we protect our patient from been over-exercised? ----------
---

Self-care

Regarding self-care, what should the rehab team teach patient during this stage?

Please, tick whether it is necessary or not necessary from the following table:

In your Opinion, who should take over to monitor the patient home programme and integration in his/her community?----------
---

Elaborate----------

Outcome of success rehabilitation

The markers or indicators for successful Rehabilitation

The patient should be independent in all self-care areas appropriate for his level of injury. **Yes /No**

Remarks ----------

The patient must have Orthopaedic clearance for gaiting. This normally occurs 6 to 8 months post instrumentation and fusion. **Yes /No**

Remarks----------

The patient must be willing to spend the necessary 4 to 6 weeks in the programme and to work 5 full days a week on gaiting exercise. **Yes /No**

Remarks: ----------

Teach the patient:	Necessary	Not necessary
Wash himself		
Teach Patient to dress himself		
Transfer from bed to wheelchair		
Self-padding and skin check		
Wheelchair mobility		
Other, specify		

The patient skin should be free of pressure sore, especially in those areas that have potential contact with the braces. **Yes /No**

Remarks:----------

The patient should express an understanding of the limitations of gaiting, including the higher energy consumption in functional/versus exercise usage. The patient also should have realistic expectations. **Yes /No**

Remarks:----------

During Sub-Acute phase of rehabilitation after a spinal cord injury disciplinary team will work on many things, please tick from the following table whether you agree or not

Rehab team should work on the following:	Agree	Not agree
getting around		
Bathing		
Dressing		
skincare		
bowel and bladder management		
Other Specify---------- ---------- ---------- ----------		

Suggestions----------

In your opinion, state the expectation from the following types of patients on discharge:

Paraplegia----------

-

Tetraplegia----------

Appendix 8: Delphi Round 2 questionnaire

1. Formation of the rehabilitation team

The following people should be included in the rehabilitation team due to the reason situated against them

	Yes	*No*
Rehabilitation team should include all the healthcare professionals to apply a multidisciplinary approach, holistic management approach and speedy recovery		
Family of the patient, to be able to deal with patient at home		
Caregivers to avoid preventable medical complications and to speed upcoming community reintegration		
Religious group for spiritual support		
Any more suggestions…… ……..		

2. Distribution of powers

	Yes	*No*
Rehabilitation process must start immediately after restoring the patient condition		
every professional must have his/her plan to deal with acute, sub Acute and chronic case rehabilitation.		
A team co-plan is important for rehabilitation of SCI, in order to achieve the long-term goals of the rehab and to		

reach to the perfect community integration		
Hand over must happen between the practitioners in the same profession		
Hand over or referral must include summary notes about patient functional level or achievements		

3. Documentation

	Yes	*No*
Documentation must include the patient's details; present Medical history, socioeconomic history, past medical history, investigations done, tests and management done, findings, diagnosis, assessments, medication and further plans		

4. Mobility and assistive devices

	Yes	**No**
When giving patient's devices, e.g. wheelchair, we must consider rural setting		
Patient must be able to manoeuvre the device for all type of environment		
Wheelchair accessories should include hand protectors, wheelie, mitts, gloves sponge, and matt to prevent skin sore		
Wheelchairs are not accessible for all patients		

The following table shows the experts suggestions to solve the challenges of mobility and assistive device distributions to the needy. Please tick where you think is right for the Ideal rehabilitation on community reintegration for people with Spinal Cord Injury

Suggestion	Yes	No
Road Accident Fund must take its responsibility toward this Matter		
All patients should be inside the medical aid umbrella, and the medical aids tale responsibility		
Disability organisation should take responsibility		

5. Home programme

Rehabilitation programme for successful community reintegration should include the following items in the home programme.

Home programme Items	Yes	No
Home programme must be clear and including the type, frequency and safety		
Written home programme should be incorporated in the rehabilitation of the patient		
Multidisciplinary team must compile the programme as a team		
Caregiver and community nurse should monitor the programme Homework		
Home visit is important to evaluate the home programme		
Introduction of the patient situation to the community must be done by Psychologist and/or Social worker whole team must introduce the situation to the community		
which of the three statement below is correct **a)** Duration of the rehabilitation should be at least 6 weeks **b)** Duration of rehabilitation should be 12 weeks to give chance to the heeling of the vertebra and soft tissues **c)** Duration of rehabilitation depend on the treatment of the injury and the speed of recovery		
Planned programme with clear goals and the collective work of the rehabilitation team should protect the patient from the been over-exercised or under-exercised		

6. Self-care

	Yes	**No**
Rehabilitation team should teach the patient during rehabilitation period haw to: wash and dress himself, transfer from bed to wheelchair, self-padding and skin check, and wheelchair mobility		
Rehabilitation team should monitor the patient's integration to the community as a team.		

Outcome of successful rehabilitation

Indicators for successful rehabilitation programme for people with spinal cord Injury should include the following:

Indicator	Yes	No
The patient should be as independent as possible in all self-care area allowed by existing muscle function appropriate for his level of injury		
The patient must have orthopaedic clearance for gait training		
The patient must be willing to spend the necessary 4 to 6 weeks in the programme and to work full five days a week to gain required strength and train new functions		

Patient’s skin should be free of bed sore		
Patient should express and understand the limitations of Gaiting		
During sub-acute phase of rehabilitation after spinal cord injury, rehabilitation team will work on: getting around, bathing, Dressing, skincare, bowel and bladder management.		
On discharge, Paraplegic patient should be able to, wash, Dress, feed himself, self-padding and skin check, wheelchair mobility		
On discharge tetraplegia (depend on the level of injury) should be able to: wash, feed, dress himself and wheelchair mobility/electrical wheelchair		
Other suggestions.....		

Appendix (9): Delphi round 3

Dear Participant, thank you for participating in the previous round 1 and round 2 of the Delphi study. As we are reaching the consensus in round 2, some of the participants sent for us some suggestions need to be addressed in round 3 (last round).

Which of the following statements is correct?

Items	Yes	No
a) The patient must be willing to spend the necessary 4 to 6 weeks in the programme and to work full five days a week to gain required strength and train new functions b) The duration of the rehabilitation programme depends on: (i) Speed of recovery (ii) Response of the patient (iii) age of the patient (iv) Patient's lifestyle before the injury (v) Injury location and type. Patient must be willing to spend the necessary time during the rehabilitation programme to gain required strength and train new functions		
The duration of the sub-acute phase of rehabilitation usually between 4-6 weeks The duration of the sub-acute phase of rehabilitation depends on the speed of the patient recovery		

Documentations

Which of the following statements is correct?

Items	Yes	No
Copy of the refereeing letters between the practitioners must be kept in the patient file Copy of the reference letters must be kept at the Practitioners department only		

Editing Certificate

Client: **EHAB ELSAYED MOHAMED**

This certificate is to record that I, Yvonne Thiebaut, have completed a copy-edit, layout and reference list check of your thesis **"REHABILITATION PROGRAMME TO ENHANCE COMMUNITY REINTEGRATION FOR PEOPLE LIVING WITH SPINAL CORD INJURIES IN RURAL AREAS OF LIMPOPO PROVINCE – SOUTH AFRICA"**.

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Qualifications: Bachelor of Arts Honours (Psychology) degree and Bachelor of Arts (Theatre Arts & Drama) degree

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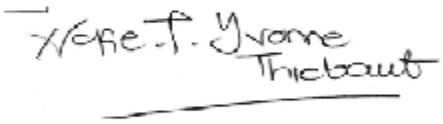

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