DESIGNING A COMMUNITY REINTEGRATION PROGRAMME FOR INDIVIDUALS WITH A TRAUMATIC SPINAL CORD INJURY IN THE CAPE METROPOLITAN AREA

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ABSTRACT

Spinal cord injury (SCI) is a devastating condition often affecting young and healthy individuals around the world. This debilitating condition not only creates enormous physical and emotional suffering to individuals but also is a significant financial burden to families and society at large and it affects quality of life. Successful community reintegration following spinal cord injury is considered an important goal of rehabilitation as this has been positively associated with self-esteem, life satisfaction and quality of life. The overall aim of the study was to design a community reintegration programme for individuals who sustained a traumatic spinal cord injury (TSCI) in the Cape Metropolitan Area. The design of this study was a mixed method design including four phases. The first phase of the study was to determine the base line information regarding reintegration into communities after sustaining a TSCI and included 108 participants. Data was collected by use of self-administered/interview administered questionnaire. The results of this phase demonstrated that community reintegration of individuals who sustained a traumatic spinal cord injury was relatively low and employment was found to be a statistically significant variable influencing community reintegration following the injury. The second phase of the study aimed to gain a deeper understanding of how employment and other factors influence reintegration into communities after the injury. This was done by exploring multiple stakeholder's perspectives regarding community reintegration of individuals with a TSCI. Individual in-depth interviews were used to collect data for this phase. Stakeholders included individuals with a TSCI that were purposively selected from phase one (n= 11), caregivers (n=6), rehabilitation professionals (n=3), members representing disabled people's organizations (n=5), members of quad-para association South Africa (n=2), as well as a member representing transportation services of individuals with disabilities (n=1). Thematic analysis in this phase identified six (6) major themes that all fall under the ICF domain of participation. Individuals with a TSCI and other stakeholders

expressed their views for what is needed for an optimal community reintegration. The results of the first two phases of the study pointed to the need to identify existing programmes that address community reintegration of individuals with a SCI through a scooping review. Ten (10) studies met the inclusion criteria for their inclusion in the review. The studies reviewed pointed to the fact that gaining meaningful employment is an important factor that influences community reintegration following a SCI. This was evident in that supported employment and mentoring programmes identified in this phase of the study played a significant role in helping individuals with SCI to gain past- secondary education and employment, promoted leisure and communication opportunities, helped individuals with SCI to achieve community independence and improved their quality of life in general. The integration of the results of these 3 phases highlighted that a successful community reintegration programme should be designed targeting three (3) different levels namely: client, community/society, as well government/legislative levels. Therefore, based on the results of these three phases, the components and strategies to be included in a community reintegration programme following a TSCI were formulated. The components included: access to both home and outdoor environment, employment, education, transportation, sports and recreational facilities, assistive devices/technologies, attitudes and counselling services. Consensus regarding the components and strategies to be included in a community reintegration programme was reached through a Delphi study. A model for community reintegration is therefore presented.

DECLARATION

I, the undersigned, hereby declare that the work contained in this thesis is my own work, that it has not previously in its entirety, or part of it submitted for any degree for examination at any other university, and that all sources I have used or quoted have been indicated and acknowledged by means of complete references.

Eugene Nizeyimana Date…….

Signature

……

Witness:

…….

Prof JS Phillips (Supervisor)

DEDICATION

In loving memory of my late father Edward Niyibizi may your soul rest in peace

To my mother Bernadette Nyirabagenzi

To my Godfather Theo Groot. You have been a source of inspiration. Without you I would not have been this far. I am who I am today because of you. Remain blessed.

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"I know **the plans** I have for you,"
declares the Lord**,**
"**Plans** to **prosper** you
and not to harm you,
Plans to give you **HOPE** and a
Future."

Jeremiah 29:11

TABLE OF CONTENTS

LIST OF APPENDICES

LIST OF TABLES

LIST OF FIGURES

Chapter One

Background of the study

"*It is not because things are difficult that we do not dare; it is because we do not dare that they are difficult.*" **Seneca** (4BC-65), Roman philosopher and playwright

Eugene Nizeyimana

1.1 Introduction

This chapter provides an overview of spinal cord injury, the rehabilitation process and the concept of community reintegration. The chapter highlights the barriers faced by individuals who sustained a traumatic spinal cord injury and particularly those barriers related to successful reintegration into their communities. Spinal cord injuries (SCI) are generally classified into two categories depending on the causes of the injury. It can be *traumatic*, when an external force is responsible for injuring nerves within the spinal column, *or non-traumatic* when injuries are caused by the infections of nerve cells, cysts or tumours pressing on spinal cord, disruption of the blood supply or congenital medical conditions (Gupta, Taly, Srivastava, Vishal, & Murali, 2008). This thesis deals primarily with community reintegration of individuals who sustained a traumatic spinal cord injuries (TSCI). The overall aim of the study and specific objectives of the four phases are also outlined in this chapter. The significance of the study is highlighted, definition of the terms and abbreviations are presented too. The chapter concludes by outlining the chapters of the thesis.

1.2 Background

Traumatic spinal cord injury is a catastrophic event that is sudden and unexpected often affecting young and healthy individuals around the world (Lee, Cripps, Fitzharris, & Wing, 2014; Ackery, Tator, & Krassioukov, 2004). This catastrophic event not only creates enormous physical and emotional suffering to individuals but is also a significant financial burden to families and society at large (Ning et al., 2011; Draulans, Kiekens, Roels, & Peers, 2011). In general, a TSCI causes life changing consequences in all facets of human functioning and existence (New & Sundararajan, 2008).

Damage to the spinal cord results in the neurological impairment affecting motor, sensory and autonomic function. Persons with paraplegia have damage to their thoracic, lumbar and sacral spinal cord and tetraplegia/quadriplegia occurs with damage to the cervical spinal cord (Ning et al., 2011). Due to the severity of a TSCI, the impact on personal, bio- psychosocial, short and long term socio- economic aspects are tremendous (Ning et al., 2011). Individuals affected by a TSCI have difficulties in performing activities of daily living, which reduces their participation in social, recreational and economic activities. Rehabilitation of persons with a TSCI is therefore, an essential to return them to their previous level of function or as close to it as possible. According to the World health Organization (WHO, 2001), rehabilitation aims not only to train people with disabilities (PWD) to adapt to their environment, but also to intervene in their immediate environment and society as whole in order to facilitate their social and community reintegration. Therefore, rehabilitation does not only include inpatient or medical rehabilitation at the rehabilitation centres but extends to post discharge from rehabilitation centres to the community setting.

For the past three decades, people living with disabilities worldwide have been engaged in a fight to remove the barriers which denied them opportunities to integrate into their communities and participate as citizens equal to their able-bodied counterparts (Mothabeng, 2011). To this end, the disability right charter of South Africa (Disabled People of South Africa (DPSA), 1993) was written in response to the demands of individuals living with disabilities in South Africa including individuals with a TSCI, for the right to adequate, accessible and affordable housing, the right to independent community life, sports and recreation as well as the right to the employment in the open labour market (Levac, Colquhoun, & O'Brien, 2010). Furthermore, the passage of the Integrated National Disability Strategy (INDS) (Mbeki, 1997) brought about hope that this policy would facilitate the removal of barriers to healthcare, education,

employment and other essential aspects of life for PWD in South Africa (Mothabeng, 2011). Unfortunately, twenty-three years later after the democracy, PWD including individuals with a TSCI still face challenges in terms of equality, and access to basic services.

People living with a TSCI have to cope with several challenges. The main challenge starts when they return home from rehabilitation centres and they have to reintegrate into their homes and their communities (Mothabeng, 2012). Long term rehabilitation of the persons with a TSCI is therefore, vital in order to help them to return to normal function or as close as it as possible (Maclachlan,2012). Rehabilitation includes all measures aimed at reducing the impact of disabling and handicapping conditions and at the enabling PWDs to achieve an important degree of self- care and social reintegration. It helps them adjust to life after a TSCI by preparing them and their families with the new skills and resources required for living in the community (De Wolf, Lane-Brown, Tate, Middleton, & Cameron, 2010).

According to Landrum, Schmidt and McClean (1995), rehabilitation should not only be provided along a continuum of care between services, it should also follow a continuum of progression in individual's lives from basic outcomes like physiological stability and prevention of secondary complications to advanced outcome such as community reintegration and employment. In order to address this progression, they proposed six sequential outcome levels through which a person should progress during the rehabilitation process (see Table1.1).

Table 1.1 Outcomes levels according to Landrum et al (1995)

Levels	Descriptions	Task to be Achieved at each Level
Level 0 Physiologic instability	Acute diagnostics and medical issues are not addressed and managed	Directly following health incident such as TSCI
Level 1 Physiologic stability	All major acute diagnostic and medical issues are appropriately addressed and managed	• Diagnosis made • Treatment planned and implemented
Level 2 Physiologic maintenance	Achievement of basic rehabilitation outcomes necessary to preserve long term physiologic health	• Client and family educated • Rehabilitation and long-term management plans in place • Strategies to prevent secondary complication in place, i.e. bladder and bowel training, prevention of chest infection, pressure sores.
Level 3 Residential reintegration	Achievement where the person can function reasonably and safely in a residential setting	• Self-care tasks performed • Mobile inn and around dwelling • Effective general communication system • Safe in a home
Level 4 Community Reintegration	Achievement of an appropriate level of function within the person's community. i.e. participate in social activities such as shopping, church and sports according to the individual needs.	• Manage personal affaires & finances • socially competent • Community mobility • Complex home- making abilities • Self- directed health management
Level 5 Productive Activity	Work at competitive level within physical, functional, and/or cognitive capabilities and appropriate to life stage & interests. This can be vocational, avocational or educational	• Environment, disabilities & job requirements play a role • Work & skills assessment, vocational training • Employment education & reasonable accommodation

Successful community reintegration following spinal cord injury is considered an important goal of rehabilitation as this has been positively associated with quality of life, self-esteem and life satisfaction (Kennedy, Lude, Elfström, & Smithson , 2012; Tonack et al., 2008; Middleton, 2007; Tate et al., 2002). Community reintegration has been defined as a states of 'resuming age/ gender/ and culturally appropriate roles/ statuses/ activities, including independence/ interdependence in decision making, and productive behaviours performed as part of multivaried relationships with family, friends, and others in natural community setting' (Dijkers, 1998). According to Kennedyet al., (2012), community reintegration leads to life satisfaction as well as a sense of competence and it is essential for psychological and economic well-being and skills development. It requires new learning, problem solving, adaptation to lifestyle changes and effective copping skills. It also helps people to make friendships, gain new knowledge, express creativity and determine purpose and meaning of life (Sekaran et al., 2010). Community reintegration is an important component of the entire rehabilitation process especially after a TSCI since this is most likely to occur in the young working individuals who have active family and social life (Sekaran et al., 2010).

Return to work and employment as part of community reintegration after a TSCI is critical, not only to secure a positive financial situation, but also impacts other aspects of life (Targett, Wehman, & Young, 2004). Positive relationships have been found between life satisfaction, adjustment after a SCI and employment status. Individuals who were employed were more active, had fewer problems, were more satisfied with their lives, and rated their overall adjustment higher than those who were unemployed (Schönherr, Grootho, Mulder, Schoppen, & Eisma, 2004). According to Krause, Edles & Charlifue (2011), return to paid work is one of the most important outcomes of reintegration in the society following a SCI. It gives people a social status and meaning to life and makes them more financially independent. As the majority

of patients with a TSCI are relatively young, attention to vocational reintegration is of particular importance, not just to the patients themselves but also from a wider social point of view (Schönherr et al., 2004).

1.3 Problem statement

Traumatic spinal cord injury tends to occur to people in their early adulthood in the prime of their lives, when they are attending schools or developing their careers, establishing a home and starting a family (Sekaran et al., 2010; Lysack, Komanecky, Kabel, Cross, & Neufeld, 2007). With the rapid advancement in the medical and rehabilitation management of persons with a TSCI in the last few decades, the life expectancy of the SCI survivors is almost similar to their able boded counterparts. Once the medical and rehabilitation team determines that they have made the sufficient gain to guarantee the discharge from rehabilitation centres, patient with a TSCI are suddenly provided with control over their health care and other important life decisions. Clearly, the rehabilitation goals of restoring patients' independence, quality of life, self-sufficiency and greater control over their lives cannot be achieved by medical rehabilitation services alone. Community reintegration after hospitalization therefore, becomes an important goal of rehabilitation at this stage. This includes physically getting to places that are not adequately accessible, as well as taking responsibility for maintenance of the various technologies that facilitate community activity (Forchheimer & Tate, 2004) . It also involves engaging in activities that may be different from those taken in pre-injury. Community reintegration thus, cannot overcome the many constraints imposed by one's disability and the surrounding environment without an intervention of different stake holders.

In South Africa, a person sustaining a TSCI is most likely to be of a male gender between 18-29 years of age and of poor social economic background (Joseph et al., 2015). Since these survivors are relatively still in early age of their lives, the expectation is that they still have future visions of living a long life with very few possibilities of returning to the highest level of functioning, namely social reintegration, but precisely return to productive living. Unfortunately, due to the scarcity of literature on rehabilitation outcomes especially regarding social and community reintegration following a TSCI, very little is known about the needs and problems of these individuals once they are discharged from rehabilitation centres and sent back to their particular communities. This study therefore, aims at deepening our understanding of community reintegration following a TSCI in South Africa and it attempts to design a community reintegration programme for individuals who sustained a TSCI.

1.4 Motivation for undertaking the study

The researcher was employed as a chief physiotherapist by the Eastern Cape Department of Health from 2006 up to 2014. During this period the researcher worked in the spinal unit most of the time and was dealing with rehabilitation of both traumatic and non- traumatic spinal cord injury patients. The researcher was working with both in- patients and out patients returning for following up appointments. It was during this period that the researcher observed that many clients returned to the rehab centre complaining about their engagement in their respective communities. The research then started engaging with patients returning for follow up in order to understand the major challenges that they face when they return back to their communities after being discharged from the rehabilitation centre. Many clients reported to be unsatisfied with reintegration into their communities after discharge. This led the researcher to gain an interest and started reading more about disabilities and disability rights, rehabilitation and

community reintegration of persons with spinal cord injuries. The information gained on rehabilitation and community reintegration was mostly from international literature and this made the researcher to think critically about rehabilitation services in South Africa more specially community reintegration following spinal cord injury. The researcher then started thinking about the following questions:

- What are the experiences of individuals who have sustained a traumatic spinal cord injury regarding community reintegration after the injury?
- What is needed for an optimal community reintegration following traumatic spinal cord injury?

The answers to above mentioned questions would serve as baseline information to inform the overall aim of this study that is stated below.

1.5 Aim of the study

The overall aim of the study is to design a community reintegration programme for individuals who sustained a traumatic spinal cord injury at least one year post the injury in the Cape Metropolitan Area, South Africa.

1.6 Objectives of the study

(The proposed study was conducted into four Phases)

Phase 1. To determine baseline information regarding reintegration into communities after sustaining a TSCI at least one year post the injury.

- To determine psychosocial reintegration of individuals with a TSCI

(i.e. Occupational activities, interpersonal relationships, living skills)

- To determine the community reintegration of individuals with a TSCI (participation, individual sense of belonging in community)
- To determine self-efficacy of individuals with a TSCI
- To determine the quality of life of individuals with a TSCI

Phase 2. To explore what is needed for optimal community reintegration

- To explore multiple stakeholder's perspectives regarding community reintegration following a TSCI.

Phase 3. To identify programmes addressing community reintegration of individuals with a TSCI

- To conduct a scoping review to identify existing programmes addressing community reintegration of individuals with a TSCI

Phase 4. To design a community reintegration programme for individuals with a TSCI

- To design and reach a consensus on community reintegration programme.

1.7 Significance of the study

For the past three decades, the focus of rehabilitation for people with a TSCI has shifted from medical management of the acute condition to issues that affects Quality of Life (QOL) and community reintegration. Community reintegration refers to an individual's ability to be an active member of the society and involves re-establishing previously existing roles and relationships (Krause, Edles, & Charlifue, 2011; Magasi, Hammel, Heinemann, Whiteneck, & Bogner, 2009). Successful reintegration into community life and employment following spinal cord injury is considered an important goal of rehabilitation as this has been positively associated with quality of life, self-esteem and life satisfaction (Dijkers, 1998). Community reintegration is in fact the most effective method of promoting positive life experiences for individuals of disabilities. It is an essential component of the rehabilitation process especially of a TSCI since this mostly occur among individuals who were young and healthy and actively integrated into social life (Sekaran et al., 2010). However, due to death of literature regarding spinal cord injury rehabilitation in South Africa more especially regarding community reintegration, very little is known about the challenges encountered by individuals sustaining a TSCI once they are discharged from rehabilitation centres back to their communities.

The main aim of the proposed study is to design a community reintegration programme for individuals who sustained a TSCI at least one year post the injury. The proposed study will be conducted in four different phases mentioned above and it is hoped that the final results of the study may be helpful as baseline information to developing the future intervention strategies and policies by all stakeholders such as individuals with a TSCI, families/caregivers, community members, employers, rehabilitation professionals and policy makers at different levels on community and social reintegration following a TSCI.

1.8 Definition of terms

- ***Community reintegration***: community reintegration refers to being part of the mainstream of family and community life, resuming normal roles and responsibilities as appropriate to people with a SCI's age, gender, and culture as well as being an active and contributing member of the society (Dijkers, 1999).
- ***Disability:*** the term "disability" refer to any restriction or lack of ability to perform an activity in the manner or within the range considered typical for a human being as a result of impairment (Chase, Cornille & English, 2000).
- ***Environmental Factors*:** The physical, social, and attitudinal environment in which people live and conduct their lives (WHO, 2001).
- ***International Classification of Functioning, Disability and Health*:** A conceptual model for evaluating activity limitations and participation restrictions in persons with impairments (WHO, 2001).
- ***Paraplegia:*** This term refers to impairment or loss of motor and/ or sensory function in the thoracic, lumbar or sacral (but not cervical) segments of the spinal cord, secondary to the damage of neural elements within the spinal canal. With paraplegia, arms functioning is spared but depending on the level of the injury, the trunk, legs and pelvic organs may be involved. (Kirshblum *et al;* 2011).

- ***Personal Factors:*** The particular background of an individual's life and living, and comprise features of the individual that are not part of health condition or health status. These include cognitive and affective of an individual such as self-efficacy, self-esteem and self-regulation (WHO, 2001).

- ***Rehabilitation:*** this is a process aimed at enabling an impaired person to reach an optimum mental, physical and/ or social functional level, thus providing her or him with the tools to change her or his own life. It can involve measures intended to compensate for loss of function or functional limitation and other measures intended to facilitate social adjustments or readjustment (WHO, 2001).

- ***Spinal Cord:*** The spinal cord is the part of central nervous system consisting of nerve cells and bundles of nerves that connect the brain with all parts of the body (Hampton & Marshall, 2000).

- ***Spinal cord injury***: A temporally or permanent deficit in sensory motor and bladder and bowel function which occurs as a result of pathology or traumatic lesion of neural elements in the spinal canal. SCI causes varying degree of loss of motor, sensory function below the level of the injury depending on the extent of the injury (Hampton & Marshall, 2000).

- ***Tetraplegia/ Quadriplegia***: this term refers to impairment or loss of motor and /or sensory function in the cervical segments of the spinal cord due to the damage of neural elements within the spinal canal. Tetraplegia/ Quadriplegia

result in impairment of function in the arms as well as typically in the trunk, legs and pelvic organs, including the four extremities. It does not include brachial plexus lesions or injury to peripheral nerves outside the neural canal (Kirshblum et al., 2011).

- ***Traumatic Spinal Cord Injury***: Injury to the spinal cord resulting from an external force such as: Assault, motor vehicle accident, gunshot, fall or stubbing.

1.9 Abbreviations Used in the Thesis

ASIA: American Spinal Cord Association

CDC: Centre for Disease Control and Prevention

CHART: Craig Handicap Assessment and Reporting Technique

CIM: Community Integration Measure

CRPD: Convention on the Right of Person with Disabilities

DA: Daily Activity

DPO's: Disabled People's Organisations

ICDH: International Classification of Impairments, Disability and Handicaps

ICF: International Classification of Functioning Disability and Health

HRQOL: Health Related Quality of Life

IR: Interpersonal Relationship

ISCOS: International Spinal Cord Injury Society

LS: Living Skills

MSES: Moorong Self-efficacy

NIH: National Health Institute

NLI: Neurological Level of the Injury

NPO: Non-profit Organization

OA: Occupational Activity

PWD: People with Disabilities

QASA: Quad-Para Association of South Africa

QOL: Quality of Life

RNL: Reintegration to Normal Living

RTA: Road Traffic Accident

SCI: Spinal Cord Injury

SE: Self-efficacy

SF: Social Functioning

SCIQOL: Spinal Cord Injury Quality of Life

SPRS: Sydney Psychosocial Reintegration Scale

SPSS: Statistical Package for the Social Science

SD: Standard Deviation

TBI: Traumatic Brain Injury

TSCI: Traumatic Spinal Cord Injury

UK: United Kingdom

UMMSCICS: University of Michigan Model Spinal Cord Injury Care Systems

UNSCISC: United State National Spinal Cord Injury Statistic Centre

USA: United States of America

UWC: University of the Western Cape

WHO: World Health Organisation

1.10 Outline of the thesis

Chapter one provided the rationale/ background of the study. It outlines the overall aim and specific objectives of the study. In addition, the problem statement and significance of the study are highlighted. Finally, the definition of the main key terms and full meaning of the abbreviations used in the study are provided.

Chapter two presents an extensive literature review that was conducted about the prevalence, incidences and causes of spinal cord injury. Rehabilitation following spinal cord injury is briefly discussed. Community reintegration and factors influencing community reintegration (Environmental and Personal factors as well as quality of life) are briefly discussed. The conceptual framework that inform this study form the last part of this chapter.

Chapter three provides all the methodological steps taken towards achieving the main aim and objectives of this study. This chapter gives a summary description of methodology employed in conducting the study. A description of research the setting is provided. In addition, a brief overview of the population, study design, data collection procedures as well as data analysis are given. Ethical considerations pertaining to this study forms the last part of the chapter.

Chapter four presents the results from quantitative data analysis which attempted to answer the objectives of the first phase of study that was to gather a baseline information regarding reintegration into communities after sustaining a TSCI. The chapter describes socio-demographic profile of individuals who sustained a TSCI, psychosocial reintegration (occupational activities, interpersonal relationships and living skills), community reintegration (participation, and individual sense of belonging in the community), quality of life and self-efficacy of individuals of a TSCI are all described in this chapter.

Chapter five provides the results of the qualitative data analysis from different stakeholders. The content analysis of individual interviews conducted is described. The interviews focused on experiences of individuals living with traumatic spinal cord injury and on views from other different stakeholders regarding what is needed for an optimal community reintegration for individuals with a TSCI.

Chapter six presents the results of the scoping literature review conducted in attempt to review the existing programmes addressing community reintegration of individuals with a SCI. International literature concerning community reintegration after sustaining a SCI is reviewed. Different steps followed during the review are described and a list of the studies included in the review is provided.

Chapter seven focuses on integrating the results of the three phases of this study in an attempt to achieve the main aim of the study that was to design a community reintegration programme for individuals who sustained a TSCI in the Cape Metropolitan Area, South Africa. The chapter summarizes the issues that emerged from first three phases of the study.

Chapter eight provides the steps followed during the Delphi study to reach consensus on community reintegration programme. This chapter focuses on the methodology, data analysis, data interpretation and summary of the chapter.

Chapter nine provides the summary, conclusion, recommendations and the study limitations.

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Chapter Two

Literature review

"Literature is where I go to explore the highest places in human society and in the human spirit, where I hope to find not absolute truth but the truth of tale, of imagination and of the heart."

Salman Rushdie (1948), Anglo-Indian Novelist

2.1 Introduction

This chapter provides a review of literature pertaining to the epidemiology of spinal cord injury, including the prevalence/ incidence, the aetiology and the rehabilitation process. In addition, the literature regarding reintegration back into the communities after sustaining a traumatic spinal cord injury and the factors influencing reintegration is reviewed. The conceptual framework of the study is also presented in this chapter.

2.2 Epidemiology of spinal cord injury

A traumatic spinal cord injury is an event that impact on physical, mental and social well- being often of young individuals and it represents a considerable financial cost to families and society at large. (Singh, Tetreault, Kalsi-Ryan, Nouri, & Fehlings, 2014). These cost are largely due to a need for high level acute care in a short term and associated secondary complications that occur in the long term (Krueger, Noonan, Trenaman, Joshi, & Rivers, 2013). Epidemiology and aetiological knowledge about SCI is therefore, essential for designing and focussing prevention campaigns especially in Sub- Saharan Countries (Draulans et al., 2011). Over the past 4 decades, SCI epidemiology has been studied extensively. Initial studies focused on descriptive epidemiology, including overall prevalence, incidences rates, age, gender, race, cause of injury, as well as level and completeness of the injury.

2.2.1 Prevalence

Prevalence is the number of people in the population living with a disease at the given time point (Singh, Tetreault, Kalsi-Ryan, Nouri, & Fehlings, 2014). It is measured as number per million population and data on prevalence of a TSCI is very important for measuring demand for health care and social support and for assessing the impact on secondary prevention

measures. Unfortunately, data on prevalence of SCI is currently scarce as there are no reliable exact global estimates of spinal cord injury prevalence (WHO & ISCOS, 2013). Never the less, a recent systematic review (Singh et al., 2014) including few studies conducted in the developed countries only indicated that the prevalence of SCI in USA was highest in the world with 906 cases per million population and the lowest in Finland and France with 280/ million and 250/ million consecutively. Although no prevalence figures are available for South Africa, the quad-para association of South Africa report (2009/2010) estimated that more than 50 000 people in South Africa were living with SCI, which corresponds to a prevalence of approximately 1000 per million populations (QASA, 2009/2010).

2.2.2 Incidence

The incidence of a disease is the number of new cases in a population at risk in a given time period (Singh et al., 2014). As per prevalence, incidences are also measured as a number per million populations. Global estimate of the SCI range from 10 to 80/ million population (Singh et al., 2014). Regional data by Cripps et al., (2011), indicated that the incidence rate of TSCI was 40 per million in North America, 16 per million in Western Europe, 15 per million in Australia, 25 per million in the Asia – Central, 21 per million in Asia South, 19 million in Caribbean, 19 per million in Latin America Indian, 24 per million in Latin America Central, 25 per million in Latin America Southern, 29 per million in Sub- Saharan Central and 21 per million in Sub-Saharan Africa East. In South Africa, a recent prospective survey (Joseph et al., 2015) indicated the incidence rate of 75.6/million population that was the highest in the world. Most of studies showed a high male to female ratio and an age of peak incidence of younger than 30 years old.

2.2.2 Aetiology

The term aetiology refer to a science and the study of the cause of the disease and their mode of operation. Identifying the causes of SCI throughout the world is important in order to understand global trends and ultimately to improve strategies for SCI prevention (Ackery et al., 2004b). There are numerous causes of SCI. Some being traumatic such as road traffic accidents, gunshots, assaults, falls and sports related injuries and non-traumatic spinal cord injuries resulting from tumours, spinal stenosis or vascular incidents.

Global TSCI varies in aetiology. Nations with similar economies tend to have similar aetiological features. For example, in the developed world, the main causes of TSCI is most likely to be Road Traffic Accident (RTA) (Knútsdóttir et al., 2012; Dryden et al., 2003). Although the most recent researches have also demonstrated that the motor vehicle accident were on a rise as the most cause of TSCI in Sub- Saharan Africa (Löfvenmark et al., 2015; Draulans et al ., 2011; Obalum, Giwa, Adekoya-Cole, & Enweluzo, 2009),violence was previously reported as the main leading cause of TSCI in Sub- Saharan Africa (Cripps et al., 2011). According to (Löfvenmark et al., 2015), road traffic accident was the leading cause of TSCI in Botswana while Draulans et al., (2011), reported that motor vehicle accidents were the main cause of TSCI in Nigeria, Senegal, Sierra Leone and Zimbabwe. In the above study, Draulans et al., (2011) concluded that an explanation to an increased case of a TSCI due to motor vehicle accident might be that in many African countries, there is currently a rapid increase of numbers of vehicles without infrastructure being updated. Moreover, many vehicles are not equipped with safety seat belts and transport in open trucks is very common which put passengers in danger.

South Africa is not exempt from the above controversial results. Previously, studies had reported violence especially gunshot and stub wounds as the main cause TSCI (Joseph et al., 2015., Hart & Williams, 1994). However, these results are controversial to those of Sothmann, Stander, Kruger, & Dunn, (2015) who conducted a retrospective review of a prospectively collected data between 2003 and 2014 and found a high incidence from motor vehicle accidents that counted 44.6%, violence was found to be second cause of the injuries counting 27.2%. The controversial results on above South African studies could have been influenced by the methodology used particularly the study design and setting in previous studies. The study by Joseph et al was a population based survey which might curry strength more than that of Sothmann et al. ((2015) which was a hospital based survey.

2.2.3 Age

Spinal Cord Injury primarily affects young adults (Noonan et al., 2012). According to United States National Spinal Cord Injury Statistic Centre (NSCISC) (2018), the average age at the injury has increased from 29 years during the 1970s to 43 years currently. The possible reasons for the observed trend toward older age at injury might include changes in either referral patterns to model systems, the location of model systems, survival rates of older persons at the scene of the accident or age- specific incidence rates. In South Africa a person sustaining traumatic spinal cord injury is most likely to be between 20 and 30 years of age (Joseph et al., 2015; Sothmann et al., 2015).

2.2.4 Gender

Men are universally more likely to be injured than females and the incidence rates for males are considerably higher than for females in all age groups (Dryden *et al;* 2003). In developing countries, male to female ratio is higher compare to high income countries (Sothmann et al., 2015; Wyndaele & Wyndaele, 2006). The reason for this might be that in low income countries

the females are more often at home taking care of families whilst men are performing the risk-taking activities outside home and being more exposed to risky working environments and violent behaviour. However, the trend in high income counties indicates that women are slowly catching up, whilst in low income settings men are still at a significant higher risk than women (Wyndaele & Wyndaele, 2006).

2.2.5 Race

A significant trend over time has also been observed in the racial/ethnic distribution of persons with spinal cord injury in database. In the United States of America, about 22% of SCI have occurred among Non-Hispanic Blacks since 2015, which is higher than the proportion on Non-Hispanic Blacks in the general population (12%) (NSCISC, 2018). According to Maclachlan (2012), coloureds were predominantly affected by a TSCI (49%), followed by Blacks (45%), whites countered (4%) whereas Asians/ Indians countered (2%) in the Cape Metropolitan Area.

2.3 Classification of traumatic spinal cord injury

According to international standards for neurological classification of spinal cord injury, the Neurological Level of the Injury (NLI) refers to the most caudal segment of the spinal cord with normal sensory and antigravity motor function.

Internationally, SCI are classified according to the American Spinal Injury Association (ASIA) (American Spinal Injury Association, 2002). The Asia Impairment Scale (AIS) is classified in 5 categories (Table 2.1).

Table 2.1 Asia Impairment Scale (American Spinal Injury Association, 2002).

ASIA A	Complete injury where there is no sensory or motor preserved in sacral segment S4-5
ASIA B	Incomplete injury where there sensory but no motor function is preserved bellow the neurological level and extends through sacral segments S4-S5
ASIA C	Incomplete injury where motor function is preserved below the neurological level, and most key muscles below the neurological level have muscle grade less than 3 (active full-range movement against gravity)
ASIA D	Incomplete injury where motor function is preserved below the neurological level, and most key muscles below the neurological level have muscle grade greater than or equal to 3
ASIA E	Normal sensory and motor functions

The segments at which normal function is found often differ by side of the body and in terms of sensory and motor testing. Thus, up to four different segments may be identified in determining the neurological level. (e.g. Right – sensory, Left- sensory, Right- motor, L-motor) (Kirshblum et al., 2011).

2.3.1 Tetraplegia/ Quadriplegia

The terms Tetraplegia or Quadriplegia refer to the impairment or loss of motor and /or sensory function in the cervical segments of the spinal cord due to the damage of neural elements within the spinal canal. Tetraplegia/ Quadriplegia result in impairment of function in the arms, the trunk, legs and pelvic organs, including the four extremities. However, it does not include the brachial plexus lesions or injury to peripheral nerves outside the neural canal (Kirshblum et al., 2011).

2.3.2 Paraplegia

The term Paraplegia is used as a reference to the impairment or loss of motor and/ or sensory function in the thoracic, lumbar or sacral (but not cervical) segments of the spinal cord, secondary to the damage of neural elements within the spinal canal. With paraplegia, arms functioning is spared but depending on the level of the injury, the trunk, legs and pelvic organs may be involved. The term is used in referring to cauda equina and corns medillaris injuries, but not to lumbosacral plexus lesions or injury to peripheral nerves outside the neural canal (Kirshblum et al., 2011).

According to NSCISC data base in the United States of America, the most frequent neurologic category at discharge of persons with SCI since 2010 is incomplete tetraplegia (45.8%), followed by incomplete paraplegia (20.9%), complete paraplegia (19.7%), and complete tetraplegia (13.2%) (NSCISC, 2018).

The literature survey by (Wyndaele & Wyndaele, 2006), that aimed to provide the overview of the literature data on incidence, prevalence and epidemiology of SCI worldwide and study their evolution since 1977, revealed that two- thirds of SCI patients are paraplegic and one- third is tetraplegic. Paraplegia was found to be more common (58.7%) than tetraplegia in Sub- Saharan Africa (Rahimi-Movaghar et al., 2013). Although no much information available about the level and extent of neurological injury in South Africa, incomplete paraplegia mainly occurring in the thoracic spine is most likely to be the common neurological level of the injury in the Cape Metropolitan Area (Sothmann et al., 2015).

2. 4 Rehabilitation following spinal cord injury

Sustaining a TSCI not only causes major changes to individual's physical and functional independence but also extended rehabilitation period means the patient's personal life style is

similarly disrupted (Kennedy et al., 2012). Although SCI is life changing situation, it does not have to undermine the possibilities of a good and fulfilling life of individuals. The impact of a SCI does not necessarily depend on the severity or the level of the injury but also on social and environmental factors. The purpose of rehabilitation following SCI is often described as being to facilitate functional recovery and independence, enhance QOL and successful reintegration of the individuals back to their community (Boschen, Tonack, & Gargaro, 2003). According to Kennedy, Evans, Berry, & Mullin (2003), rehabilitation should be a dynamic process, assessing the individual on skills appropriate to their functional capabilities and personal goals and thus assisting them to be fully integrate back into their communities. Spinal cord injury rehabilitation is the only intervention that ensures a successful community reintegration of a SCI patient as an active member. In the developed world, rehabilitation is a continuum of care available to most, if not all SCI patients (Rathore et al., 2008). Spinal cord injury medicine is established as a sub-specialty in many parts of the developed world. However, spinal cord injury rehabilitation is poorly developed in the Sub- Saharan countries and is often confused with physiotherapy, rather than a concept of multidisplinary approach as the number of the specialists trained in the SCI rehabilitation medicine is still very small in many developing countries (Rathore et al., 2008).

In South Africa, the public health care system has undergone radical changes after 1994 after match of apartheid with philosophies and perceptions focussing on availability of health care as a basic human right. Having access to affordable and quality of health care including rehabilitation of individuals with disabilities was identified as the primary vehicle for health services delivery. Currently, both public and private funded health care systems are available, with approximately 80% of South Africans using the public system (Joseph, Mothabeng,

Scriba, & Wilson, 2017). A community- based study by Maart Jelsma; (2014) concerning access to public health and medical rehabilitation services revealed a high number of unmet rehabilitation needs such as home- based care (54%), assistive devices (34.5%), medical rehabilitation services (28.9%) and health services (2.5%). The main problems were access to transport and inadequate finances. There are 24 private and government –funded rehabilitation facilities in South Africa and none of them offers comprehensive rehabilitation programs that are multi-sectorial and multidisciplinary. Rehabilitation interventions provided in such institutions are mainly medical with limited attempts to prepare those with spinal cord injuries for social and community reintegration (Joseph, Scriba, Wilson, Mothabeng, & Theron, 2017).

2.5 Community reintegration following disabilities

Community reintegration has not only become the focus and an ultimate goal of rehabilitation for people living with disabilities including individuals with a TSCI, but also an important objective and aim of public policy and legislation (Mothabeng, Eksteen, & Westaway, 2012). Although an extensive effort has gone into the development of a comprehensive and consensual definition of community reintegration, several authors have agreed that community reintegration is a multi-dimensional concept and includes a common features or idea such as: residential setting, an appropriate social network, community activities and accepting responsibilities as an equal member of the society, productive activities such as employment, education and voluntary work as well as interactive relationships with family members, friends and the larger communities (Parvaneh & Cocks, 2012; Yasui & Berven, 2009; Ware et al.; 2007; Dijkers, 1998; Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993). According to Dijkers (1998), a definition pertinent to the SCI population states that community reintegration is resuming age, gender, and culturally appropriate roles/status/activities, including

independence/interdependence in decision making, and productive behaviours performed as part of multivaried relationships with family, friends and others in natural community setting. The term "participation is also often used to capture this construct and is broadly defined by WHO as involvement in life situation (WHO, 2001).

According to Minnes et al., (2003), community reintegration should be described in two different ways including objective and subjective definition. Objectively, community reintegration can be described as how often and how independently the individual can participate in daily activities such as home activities, social activities, and or productive activities while subjectively, it can be described as the person's perception of their abilities to reintegrate into their communities but not the actual participation. As the social aspect of functioning, reintegration is achieved through a person's roles in family, community and the larger society and, as such is a highly valued rehabilitation outcome for individuals with disabilities including those of a TSCI, their caregivers and the society at large (Magasi et al., 2009). According to Cieza et al., (2010) ; Whiteneck et al., (2004), community reintegration refers to an individual's ability to be an active member of the society and involves re-establishing previously existing roles and relationships. It includes issues of active and meaningful engagement in the society, choice and control, as well as access and opportunity (Heinemann et al., 2013; Chapin & Kewman, 2001). According to Müller, Peter, Cieza, & Geyh (2012), one measure of the success of a TSCI rehabilitation is the level of participation within the community post discharge. However, many individuals with a TSCI continue to have a significant disabilities and often require long term assistance with transitioning back into their communities. Consequently, the severity of heir impairment and disabilities as well as physical barriers often affect their ability to successfully reintegrate back to their communities. According to Kennedy et al., (2012), community reintegration leads to life

satisfaction as well as a sense of competence and it is essential for psychological and economic well-being and skills development.

For the past 2 to 3 decades, rehabilitation process has moved towards community reintegration of individuals of disabilities including individuals with a TSCI as they return home and communities from specialized rehabilitation centres (Gómara-toldrà, Sliwinski, & Dijkers, 2014; Magasi et al., 2009). One of the main areas of the environment includes the individual's personal living space (Stiens, Kirshblum, Groah, McKinley, & Gittler, 2002) and factors related to access to the home (Hurst, 2003). Residential reintegration therefore, is considered as the first stage of community reintegration (Stiens et al., 2002). Dijkers, (1998), stated that community living describes the situation of an individual who fully participates in all aspects of social life of his or her family, community and society. He concluded with a statement that residential setting should be considered an important as participation at this level is the first step towards social and community reintegration. The study conducted by Kennedy, Lude, & Taylor (2006) evaluating quality of life, social participation, and appraisals and coping post spinal cord injury in four European community samples revealed that the majority of participants believed that specialised treatment or home based care rather than general rehabilitation would meet their needs. When asked what treatment would most likely to address the participants' needs, the most frequent answer which countered 23% of all responses was residential training in the specialised SCI centre with psychological and physiotherapeutic care.

2.5.1 Community reintegration in South Africa

Although the South African department of health adopted various frameworks and policies to ensure the health and well-being of individuals with disabilities, and the national rehabilitation policy clearly states that achieving advanced outcomes levels of rehabilitation such as community reintegration and productive activity should be the focus of the rehabilitation services, there is still a big gap as rehabilitation does not often progress beyond the basic outcomes such as mobility and health self-care. Thus, achieving community reintegration and productive activity is often difficult among SCI population in South Africa. Very few studies discussing community reintegration or the ideas related to community reintegration following disabilities were conducted in South Africa (Mothabeng, et al., 2012; Mdzi, Stewart &Musenge 2013.; Maleka, Stewart & Hale, 2012.; Hassan, Visagie & Mji, 2012; Rhoda, Mpofu & Deweerdt, 2011.; Mothabeng et al., 2011.; Wasserman, De Villiers & Bryer 2009). However, none of these studies have discussed community reintegration through the multidimensional approach to address its complexity. It is therefore, against this backdrop that the current study aimed at looking the level of the community reintegration through a multidimensional approach. The study will report at both objective and subjective community reintegration for individuals who sustained a TSCI in South Africa. In addition, self-efficacy and quality of life of these individuals will be reported too. The results will partly serve as a baseline information to designing a community reintegration programme following a TSCI in South Africa.

2.6 Factors influencing community reintegration following a SCI.

The ultimate rehabilitation outcome for persons with SCI is to fulfil their social role and optimize community reintegration. Unfortunately, many persons with SCI are restricted in

these aspects due to individual and environmental factors. Previous studies has reported improved quality of life and adjustment after SCI if community reintegration concerns are included during the rehabilitation process (Tonack et al., 2008; Tate *et al;* 2002).The ICF illustrates the dynamic interaction between health condition, body function and structures, activities, participation, and contextual factors (Hawkins, McGuire, Britt, & Linder, 2015). In particular, participation is described as being affected by impairment, activity limitations, environmental factors and personal factors (WHO, 2001). Impairment and activity limitations, personal and environmental factors that facilitate or hinder the participation/ community reintegration after SCI have been investigated in order to direct intervention as well to promote optimal adjustment and enhance quality of life (Barclay, Mcdonald, Lentin, & Bourke , 2016; Hawkins et al., 2015; Dwyer & Mulligan, 2015; Suttiwong, Vongsirinavarat, Chaiyawat & Vachalathiti 2015; Geyh et al., 2012; Kennedy et al., 2012; Martin Ginis et al., 2011; Lysack et al., 2007). Impairments and activity limitations that identify aspects of functioning also predicts the amount of community Reintegration (Whiteneck et al., 2004).

2.6.1 The influence of personal factors on community reintegration

Personal factors include features of an individuals that are not part of a health condition. These are Socio-demographic and injury variables such as age, gender, Educational Status Marital status, Employment status, Ethnicity and time of living with the health condition etc. in addition, motivation, self-efficacy/self- esteem, and self-regulation are also considered as personal factors that influence community reintegration following SCI. The presence of some of these personal characteristics have been found to have either positive or negative influence on community reintegration. For example, studies investigating life satisfaction after SCI in the Canadian sample found that educational level was very important personal factor

influencing community reintegration, in addition to age at the time of the injury, level of the injury, time since the injury, gender, and marital status and employment status (Tonack et al., 2008). It has also been reported that the personal variables might have a negative influence on environmental barriers to community reintegration. For example a study by (Whiteneck et al., (2004) that aimed to explore the relationship of gender and environmental barriers and societal community integration found that gender was positively associated with environmental barriers. Women reported having environmental barriers more frequently than men. Aggregating across the CHIEF's scales, women had higher CHIEF scores indicating that they reported greater combined barrier prevalence and intensity across domains.

Positive self- efficacy, self- esteem and self- regulation has also been associated with greater community reintegration following spinal cord injury (Hawkins et al., 2015; Geyh et al., 2012; Bandura, 1977). Self- efficacy is the belief that each individual has about his or her ability to produce the desired outcomes when performing specific activities and pursuing a desired goals and one's sense of self-efficacy guides goal selection and persistence. Individuals with high self-efficacy beliefs persist in challenging circumstances and strive to must each situation while people with low self-efficacy are less likely to persevere as the obstacles are encountered (Bandura 1977). This concept is particularly important related to the disabilities, as individuals with disabilities are likely to experience a wide range of obstacles in their daily life, from those related to limitations in functions, to attitudinal and structural barriers in the society (Miller, 2009).

A study by Geyh et al., (2012), that aimed to determine the relationship between self-efficacy/ self- esteem and participation following spinal cord injury revealed that positive self- efficacy and self- esteem highly correlated with participation. There were stronger correlates of participation than symptoms of anxiety, depressive symptoms, pain, health conditions, social support, coping styles or sense of coherence. However, participation seemed to be independent

of gender, age, level or completeness of the injury. Self- efficacy and self- esteem explained together with time since discharge and years of education with 48% of the variance in participation adjusting for health condition, depressive symptoms, pain interference and social support. A review article published by Benight & Bandura, (2004) on perceived self-efficacy and recovery from post-traumatic experiences revealed that perceived self-efficacy served as a mediating variable to post-traumatic recovery across multiple types of traumatic events. In general, the individuals who believed that they had ability to take control over their lives were better at overcoming their situation instead of allowing their circumstances direct their lives. These could mean that SCI individuals with high self- efficacy might reintegrate better in the community compared with those with negative low self-efficacy. According to (Hawkins et al., 2015), positive self-efficacy, personal motivation were positively associated with community reintegration of service members (including SCI individuals) injured in the global war on terrorism. Martin Ginis et al., (2011), studied personal variables included in Social cognitive theory and how these variables predicted participation in physical activity among individuals with SCI. The findings indicated that self- regulation (eg. goal setting, planning) was positively associated with physical activity although self-efficacy did not have a direct significant effect on physical activity participation. In their conclusion, the authors attributed the findings to the nature of disability indicating that individuals with SCI often have to plan ahead to negotiate the various barriers prior to participate in physical activity. Therefore, these regular routine of planning ahead might have hindered the significance of self-efficacy.

2.6.2 The influence of environmental factors on community reintegration

Environmental factors are part of contextual factors that represent the background of an individual's life and living. Currently, the International Classification of Functioning,

Disability and health (ICF), recognizes the extend of social disadvantage experienced by individuals with disability including SCI individuals who participate in the society (WHO, 2001). The ICF model moves us from a longstanding preoccupation with re-entry of damaged bodies into the normal society thus, rehabilitation's early reliance on the idea of community reintegration (Boschen et al., 2003). The environmental factors that influence community reintegration include: physical (e.g. architecture), cultural (e.g. attitudes, beliefs) as well as social (e.g. family and friends). Environmental factor can also act as facilitator or barriers to community reintegration. A survey conducted by (Whiteneck et al., 2004) investigating the role of environmental factors on the community participation of 2762 individuals with SCI in the United State of America (USA) who have been living with SCI between one and twenty five years found that the perceived top five environmental barriers were those in the natural environment, transportation, help at home, health care and government policy as reported by the Graig Hospital Inventory of Environmental Factors (CHIEF). The same five barriers were identified (but in different descending order) in the similar study conducted by (Lysack et al., 2007) that aimed to explore the relationship between perceived environmental barriers and perceived community reintegration in a sample of adults with TSCI. Furthermore, the study by (Ripat & Woodgate, 2012) that investigated self-perceived participation among adults with SCI in Canada revealed that community access was a key facilitator of participation in the community. Accessible environments supported people's engagement in important and meaningful activities. Those of long standing injuries commented on the improvements they had seen over the years in term of architectural accessibility and attitudes with more awareness of the rights of the people with disabilities.

The following table provides the reader a summarised format of the studies that discussed the influence of environmental and personal factors on community remigration following SCI

The table 2.2 Studies that discussed the environmental and personal factors that influenced community reintegration following SCI.

AUTHORS & YEAR	STUDY DESIGN	AIM OF THE STUDY	STUDY LOCATION	MAIN RESULTS	RESEARCH IMPLICATIONS
Barclay *et al* ;2016	A cross-sectional survey	To identify facilitators and barriers to social and community participation following spinal cord injury	Australia	Resources and environmental accessibility, health issues, adequate financial resources and social support from family and friends were found to assist social participation whereas the physical environment, unsupportive social attitudes and mental health issues were identified as barriers to community reintegration.	The findings of this study indicates that enabling engagement in meaningful activities in the community must be at the forefront of rehabilitation intervention, both at an individual level and through advocacy and policy involvement to improve quality of life of individuals with SCI living in the community.
Dwyer & Mulligan, 2015	A cross-sectional survey	To determine what individuals with SCI perceive as barriers and facilitators to community reintegration following SCI	New Zealand	Accessibility of the environment, re-establishing self, social support were significantly associated with better reintegration	The finding of this study indicates that health professionals working with individuals with SCI have to be client- centred and ensure that each individual needs are suitably met to support and re-connect with their work and community life.

Hawkins et al, 2015	A cross-sectional survey	To investigate the influence of contextual factors on community reintegration among service members injured in global war on terrorism	USA	Social support (families and friends), Vocational rehabilitation programs, governmental polies, peer mentoring, adapted sports, positive self-efficacy, personal motivation, school, work and volunteering were significantly associated with better community reintegration. Whereas poor rehabilitation, low self- efficacy, lack of motivation , inadequate goal setting, attitudes, lack of support and stigma was associated with poor reintegration	The findings indicated that the roles of social support, and personal factors such as high self-efficacy, personal motivation are the primary means of being reintegrated into the homes and communities. In addition, developing inclusive government policies is very important for better reintegration following the injury
Suttiwong *et al*; 2015	A cross-sectional survey	To identify the predictors of community participation after spinal cord injury	Thailand	The key predictors of community reintegration were the availability of social support and individual's functional performance.	The finding of this study indicates that these predictors should be emphasized when developing interventions in rehabilitation and community reintegration.
Geyh *et al;* 2012	A cross-sectional survey	To examine the relationship of self-efficay and self-esteem with participation of person with SCI from comprehensive bio-psycho-social	switzerland	Self-esteem and self-efficacy correlated highly with participation and were the strongest correlates of participation. Participation seemed to be independent of gender, age, level of completeness of injury. Self-efficay and self-esteem explained together with time since discharge and years of education 48% of the variance in participation adjusting for health condition, depressive symptoms, pain interference and social support.	The findings of this study idicates that considering self-efficacy and self-esteem within the comprehensive framework of the ICF can contribute to a better understanding of functioning, disability and health in SCI, which in turn may facilitate the development of interventions to support the person's adjustment and community reintegration.

		perspective based on the conceptual framework of the ICF			
Lysack *et al;* 2007	A cross-sectional survey	To explore the relationship between perceived environmental barriers and perceived community integration in the sample of TSCI	USA	The natural environment and the policies of government were the most problematic. Level of community integration were also high. Data suggests significant relationship (P<.01) between perceived environmental barriers and community integration for adults with SCI, proving support for the ICF model.	The findings suggest that improved measures and more sophisticated concepts and theories are needed to explicate the relationship between environmental factors and participation concepts in the ICF. rehabilitation team need to be aware that removal of environmental barriers is only the first step in the more complex effort to facilitate optimal community integration after SCI.

2.6.3 The influence of Quality of life on community reintegration after spinal cord injury

The purpose of rehabilitation is to facilitate functional recovery and independence, enhance quality of life (QOL) and successfully reintegrate the individual back into their community (Boschen et al., 2003) . It is believed that QOL after SCI is an essential aspect of rehabilitation and a key outcome to be used in determining the effectiveness of community reintegration (Hammell, 2004; Dryden et al., 2003). With many authors considering it to be the ultimate outcome for rehabilitation interventions (Hammell 2004, Lee & Mc Commick 2004, May & Warren 2002), QOL has been reported to be lower in individuals with SCI compared to the normal population (Barker et al., 2009; Duggan & Dijkers, 2001; Hampton & Qin-Hilliard, 2004; Hicks & Ginis, 2008).

While the need to understand more about the perceptions of quality of life held by individuals with SCIs is unchallenged, there have been difficulties in studying a concept that lacks a clear definition and that is perceived differently by different people at different times of their lives (Tate, Kalpakjian, & Forchheimer, 2002). Subsequently, the majority of researchers into QOL following SCI has adopted a quantitative approach reflecting research's assumptions that quality can be measured quantitatively. This means that determinants of QOL following a SCI can be reliably predicted by able bodied researchers and that the subjective experience of life can be objectively and accurately determined by another person (Hammell, 2004). It has been suggested that how someone attempts to measure QOL says more about their own values, priorities and fundamental orientation to life than it does about the QOL of the people whose lives are ostensibly being studie. Quantitative research is hypothesis driven, requiring researchers to predetermine the variables to be measured and thus to identify in advance those factors that are relevant and important to the issues under investigation. However, this surely limits the range of possible findings (Hammell, 2004).

Recognising the essential problems with attempts to quantitatively measure QOL among people of SCI, many researchers have advocated the use of qualitative methods that can explore both the meaning of QOL of people of SCI and factors identify as contributing to the experience of quality in their lives. To ascertain this, Hammell, (2004) suggested the use of meta-synthesis to identify those factors that people with SCI perceive as contributing to , or detracting from experience of a life worth living and proposed this might provide an evidence –based foundation for further rehabilitation practice and for future research into life after SCI. The same author (Hammell) conducted a meta-synthesis of qualitative findings to address his own suggestion of 2004. The results of meta-synthesis revealed that QOL was diminished by problems associated with the impaired body and by a sense of loss. The experience of worth living QOL was found to be enhanced by meaningful relationships, the assumption of responsibility for, and opportunity to exert control over one's own life and the ability to engage in personally meaning occupations, hence, community reintegration (Hammell, 2007).

Despite being considered as an important part of rehabilitation process, especially after TSCIs as this tend to occur among young people, little have been discussed and there is a still a gap regarding community reintegration following TSCI in South Africa. Although the South African National Policy (SANP) documents the comprehensive service framework for the implementation of health care plan 2015-2020, South Africa is failing to implement comprehensive rehabilitation practice that includes community reintegration following disabilities.

2.6.4 The influence of self-efficacy on community reintegration following spinal cord injury

Self- efficacy (SE) is an important concept cited in literature relating to successful community reintegration and QOL following SCI. According to Bandura (2001), self-efficacy is defined as a person's belief that they have the skills and ability to take control of a circumstance and overcome challenges as it relates to specific behaviour, not a characteristic of a person's personality. SE is the primary concept representing internal personal factors and it influences an individual's pessimism or optimism, decisions on whether to undertake challenges, effort to overcome challenges and perception of failure or success as motivating or demoralizing (Bandura, 2001). Some other authors refer to a similar concept of "locus of control" that is described as "the degree that individual expects that a dependent relationship exists between one's behaviour and outcomes (Rotter, 1966). Bandura states that an individual who believes that he or she has skills, confidence, ability, and control to overcome a challenges will be more likely to make an effort to overcome the challenges and sustain that effort (Self-regulation). Thus, individuals with higher self-efficacy may face similar challenges as their peers but they are more psychologically capable of overcoming those challenges than making them more likely to sustain their goals.

It has been reported that individuals with SCI lack confidence in their abilities and have lower self-efficacy compared to the able bodied population. In cross-sectional study with multiple independent measures to explore the relationship between QOL and self-efficacy in a sample of over one hundred individuals with SCI, Middleton et al., (2007) found a significant relationship between self-efficacy and QOL($p<0.001$) with higher self-efficacy related to better QOL. Boschen et al., (2003) carried out a mixed method study (Quantitative & qualitative)

with an aim to look at a long term adjustment and community reintegration following a SCI, and the results indicated that locus of control was a predictive of satisfaction with performance of daily activities, satisfaction with community reintegration and QOL. The authors concluded that locus of control as it relates to self-efficacy was an essential component to adjustment following a SCI and an important component in QOL. A "fitting spirit" and acceptance coping strategies to assist with the adjustment following a spinal cord injury have been linked to internal control that is a component of self-efficacy. For example, a study conducted by Kennedy et al., (2006) in four European countries to determine the community needs of individuals with SCI indicated that participants used a "fighting spirit" and acceptance coping strategies to assist with the adjustment. Block et al., (2010) evaluated a health promotion and capacity building programme ("Shake it up") to determine the befits of the programme in a number of areas including self-efficacy. The results indicated that participants who attended the programme had a significant improvement in self-efficacy. In addition to self-efficacy, there was an accomplishment of a number of goals that the participants had individually set, increased motivation and feeling empowered to make changes in their lives. The relationship between participation and self-efficacy appears to be a "catch 22" situation as by improving self-efficacy the individual become more confident, thus increasing their levels of participation, which in turn leads to a further increase in self-efficacy. This relationship further results in an increase in QOL (Hicks & Martin Ginis, 2008). A study conducted by Sakakibara et al., (2014) to investigate the direct and mediated effects of self-efficacy on participation frequency in the community- dwelling wheel chair users (including individuals with SCI) aged 50 years or older, indicated that self-efficacy directly and indirectly influenced the participation frequency in the community. Higher levels of self-efficacy acted to improve life-space mobility and perceptions about participation limitations which in turn lead to more frequent participation.

Authors concluded that strategies to improve low self-efficacy may have beneficial effects on participation frequency.

2.7 Conceptual framework of the study

This research was informed by the International Classification of Functioning Disability and Health (ICF). In order to understand the ideas of this approach and how it informed the particular research, a brief overview of the ICF background is provided.

The ICF was developed by the World Health Organization (WHO, 2001) as a replacement to International Classification of Impairments, Disability and Handicaps (ICIDH) that was criticised for not allowing measurements of environment and social barriers or facilitators in the process of disablement. The purpose of the ICF is to provide a standard language and framework for description of human functioning and disability for common use in the everyday work by the multi-professional team (Rentsch et al., 2003). Since the ICF uses a bio-psychosocial approach to address issues of disability and functioning it would be the appropriate conceptual framework to address this study.

The ICF attempts to include all aspects of human health and some health-relevant components of well- being and describes them in terms of *health domain and health- related conditions*" (WHO, 2001). The ICF places those health related domains into two (2) broad categories namely: (1) functioning and disability and (2) contextual factors. Functioning and disability includes two components which are body function and structure and activity and participation. Contextual factors include two components as well namely: environmental factors and personal factors (WHO, 2001).

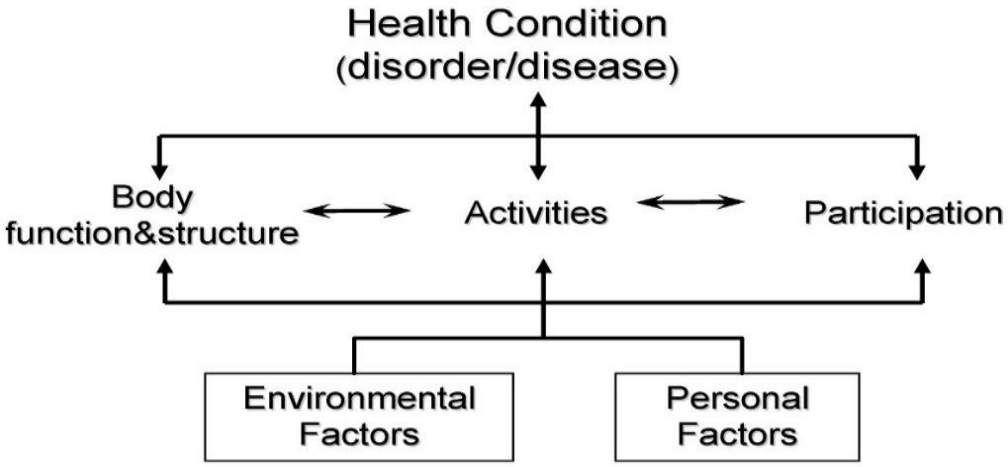

Fig 2. 1. ICF Conceptual frame work (Source: WHO, 2001 Geneva, Switzerland)

According to the ICF, Body function and structure refer to the anatomical and physiological functioning of individuals. Activity and participation refers to a task or action and person's ability to execute the task or action in a life situation. Contextual factors (Environmental and Personal) refer to physical, social and attitudinal environment in which people live and conduct their lives (WHO, 2001). However, the WHO has not fully determined personal factors to include in the ICF. The environmental factors are the main components within contextual factors quota of the model at this time. This study will use the ICF's environmental factors to determine the influence of the environment on a person's ability to successfully reintegrate into their home and communities following a TSCI. The environmental factors are conceptualized in the five domains namely: (1) natural environment and human made changes to the environment, (2) products and technologies, (3) support and relationships, (4) attitudes and (5) services, systems and policies. According to the ICF model, these components can act as facilitators and or barriers to community engagement. Therefore, these components will be critical in this research design and data analysis in order to understand their influence on

individual's ability to participate in the community. Using the ICF's framework of the environmental factors will determine how physical, social, and attitudinal environment affect community reintegration of individuals with a TSCI and will help in designing a community reintegration programme following a TSCI.

2.8 Summary of the chapter

A considerable amount of literature has been discussed about traumatic spinal cord injuries, rehabilitation process as well as community reintegration worldwide. According to literature, rehabilitation should enable a person to achieve independence, social and economic self-sufficiency and improve quality of life. Successful community reintegration on other hand is considered as a key component and contributor to quality of life for individuals of a SCI. It is most likely however, that contextual factors (Environmental and Personal) that fall into participation domain of the ICF can negatively or positively influence community reintegration following SCI. According to literature community reintegration following disabilities should be measured both subjectively and objectively in order to gain more accurate understanding of reintegration. The literature also pointed out that QOL after SCI is an essential aspect of rehabilitation and a key outcome to be used in determining the effectiveness of community reintegration. However, QOL has been reported to be lower in individuals with SCI compared to the normal population. In addition, self-efficacy has also been reported to influence both subjective and objective community reintegration following the injury. Therefore, the interaction of community reintegration, self-efficacy and QOL demonstrates that community reintegration is a complex phenomenon that needs a measurement of more than one construct. Very few studies have discussed community reintegration or the ideas related to community reintegration in South Africa but none of them have looked reintegration through this multidimensional approach to address this complexity and none of them were conducted specifically on a TSCI individuals. It was therefore, against this gap that the present study aimed to measure community reintegration through a multidimensional approach and it attempts to design a community reintegration programme for individuals who sustained a TSCI in the Cape Metropolitan Area.

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Chapter three

Materials and Methods

"Our goals can be only reached through a vehicle of plan, in which we must fervently believe, and upon which we must vigorously act. There is no other route to success"

Pablo Picasso, 1881-1973, a Spanish poet and playwright

3.1 Introduction

This chapter provides an overview of all the methodological steps taken towards achieving the main aim and objectives of this study. The research setting of the overall study is explained in details with an illustration of its location included. A brief description of population, study design, data collection procedures as well as data analysis for each specific phase is provided. Ethics pertaining to this study is also outlined.

3.2 Research setting

The study was conducted in the Cape Metropolitan Area of the Western Cape Province, South Africa. According to Statistics South Africa (Census, 2011), the Western Cape Province has a population size of 4.136.846 and the Cape Metropolitan Area has a population size of approximately 3.7 million on a 2500 km2 landscape. Approximately 222.333 (5.4%) population in the Western Cape are living with disabilities. The Cape Metropolitan Area was used because of its ethnic diversity. The predominant population group in this district is Coloured (42.4%) and others include Black (38.6%), White (15.7%) and Indian/Asian (1.4%). Afrikaans is the language spoken by most of the population, followed by isiXhosa and English (Census, 2011). In this particular study, all the above mentioned racial groups where included although only Coloureds, Blacks and Whites participated in the study. The smallest number of Indian/Asian population (1.4%) could be the reason why this racial group was not represented in the study. The race/ethnicity variables were based on the former government's classification system (i.e. Black, Coloured, White and Indian/Asian). Although the author acknowledges that using "racial" labels is ill perceived, these descriptions continues to influence individual's socio-economic status and their communities where they live. Ellision, De Wet, Ijsselmuiden and Richter (1996) caution that there are dangers of analysing data by race classification

because the groups do not have anthropological or scientific validity. However, there are still differences among the groups for many indicators of health, mediated by political and economic factors. Prior to 1994, fewer resources and funding has been allocated to the Black population in South Africa. The inadequacies and inequalities in the system of the apartheid regime reflected and reproduced the socio-economic disadvantages that was experienced marginalized racial groupings. Therefore, in this this study the use of the race/ethnicity refers explicitly to the social indication of race.

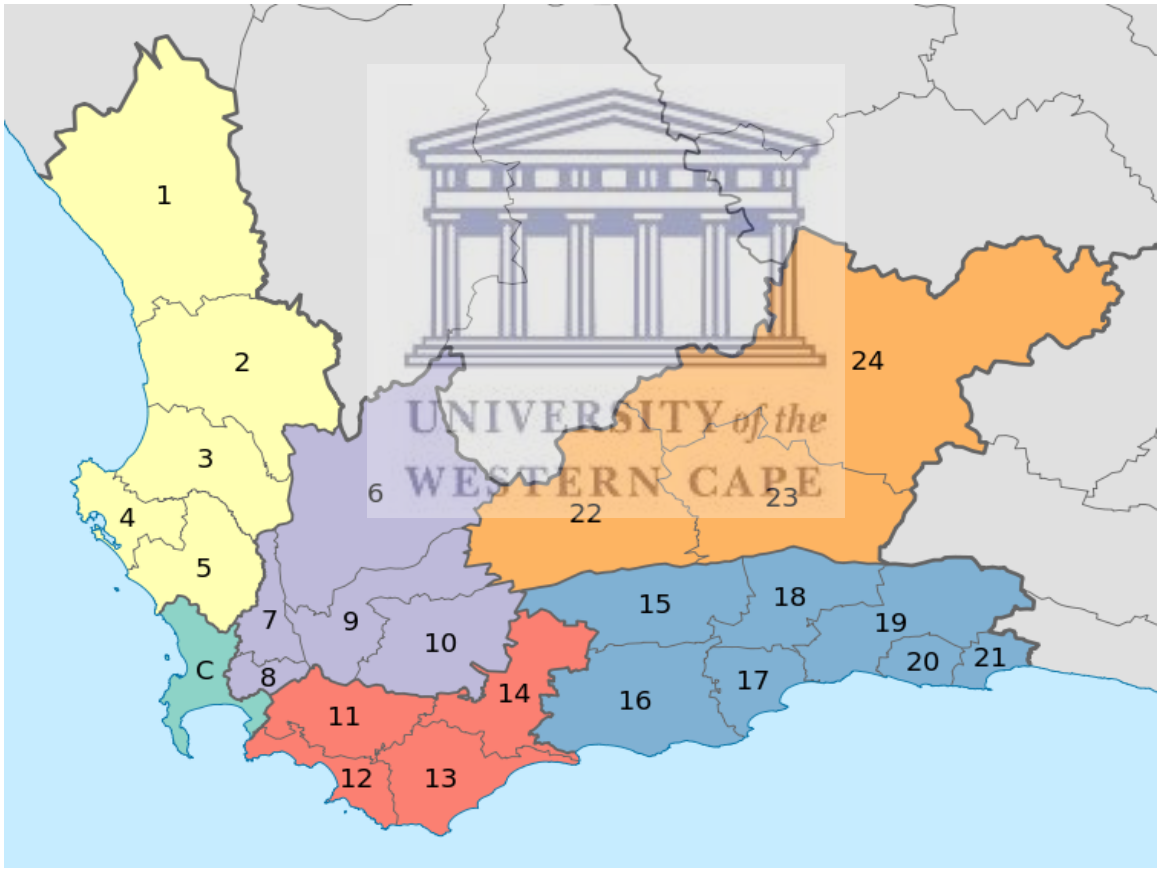

Figure 3.1 Map of the Western Cape district municipalities. 'C' represents the Cape Metropolitan District

3.3 Study design

The design of this study was a mixed method design (the combined use of Qualitative and quantitative methods). The parallel mixed design was specifically used. With this type of design the Qualitative and Quantitative strands are planned and implemented to answer related aspects of the same overarching question (Creswell & Plano, 2011;Teddlie & Yu, 2007). A strength of quantitative data is the generalizability to a larger population, however, quantitative data generally lacks the depth of understanding on the individual level. on the other hand, a strength of qualitative data is the breadth of understanding a phenomenon at an individual and small group level but it lacks the generalizability to the larger population (Onwuegbuzie & Johnson, 2004). Primarily the participant selection variant was used where by the quantitative data was collected first to identify and purposefully select participants for the qualitative phase. Then in-depth face to face qualitative data was purposively collected from participants that participated in quantitative phase in order to aid in explaining and expanding the quantitative results. Creswell and Plano, (2007) argue that the use of qualitative and quantitative approaches in combination may provide a better understanding of research problems and complex phenomena than either approach alone. In this particular study, quantitative data was used to determine baseline information regarding reintegration of individuals of a TSCI into the communities. The qualitative data collected as follow up to the quantitative results, further explained the experiences of individuals with a TSCI with regards to community reintegration after the injury. Furthermore, qualitative data explored the views of various stakeholders on what is needed for an optimal community reintegration following the injury. Data from the quantitative and qualitative results were then merged to create a more comprehensive understanding of community reintegration of individuals with a TSCI.

3.4 Overview of the methods of data collection

Table 3.1 provides a brief description and summary of the methods used to answer the objectives of each of the four (4) phases of the study. The study design, study sample, methods of data collection and analysis are provided. A detailed account of the methods of data collection is unpacked and provided in the relevant chapters. The reliability, validity and trustworthiness pertaining to each of these phases are discussed in the relevant chapters.

Table 3.1 Research designs, populations, data collection procedures and analysis for the phases of the study

Phases	Study design and Method	Study sample	Data collection procedures	Data analysis
Phase 1. Baseline information regarding reintegration into communities at least one year post injury	Quantitative design (A cross-sectional survey)	One hundred and eight (108) individuals with TSCI ≥ 18 years of age who have lived with a TSCI for an average of 10.2 years.	Self- administered/ interview administered questionnaire that includes the Sydney psychosocial reintegration scale (SPRS-2), Community reintegration measure (CIM), Spinal Cord Injury Quality of life (SCIQOL) and the Moorong Self- efficacy Scale (MSES).	Descriptive statistics and frequency counts were used to summarize the sociodemographic data of the study sample. T-tests, one-way analysis of variance (ANOVA) and chi-square tests were used to examine sociodemographic and injury factor differences within the sample. Alpha level was set at 0.05.
Phase 2. Multiple stakeholders' perspectives regarding community reintegration of individuals with a TSCT	Qualitative design (Individual face to face interviews)	A total of twenty eight (28) participants including: individuals with TSCI (n=11), Caregivers (n=6), Rehabilitation professionals (n=3), Members representing disabled people's organizations (n=5), members of quad-para association (n= 2), a member representing transport services (n=1)	Individual tape recorded face to face interviews were carried out by principal researcher.	Transcription of the information from the audiotape recordings to produce manuscripts. A comparison was made with the notes taken during the interviews to verify the accuracy. Notes were made throughout the reading of the transcripts and the data was coded in the themes, followed by sub-themes of emerging themes which fit together.
Phase 3. Review of programmes addressing community reintegration of individuals with a SCI.	A scoping literature review	Studies including individuals with TSCI ≥ 18 years	Review of programmes addressing community reintegration following a TSCI	Analysis in this phase of the study involved a descriptive numerical summary of included studies. A total of 10 studies addressing community reintegration programmes were summarized under the following headings: Authors, Year of publication, aim of the Study, Study location, type of intervention, main results and implications of the main results.
Phase 4. Design and reach consensus on components and strategies to be included in a community reintegration programme for individuals with a TSCT	A Delphi technique	10 experts in the field of spinal cord rehabilitation	Proposed components and strategies for the programme to be designed was sent to 10 experts in the field of spinal cord injury rehabilitation for their opinions and consensus	10 experts in the field of spinal cord injury rehabilitation provided their opinions on the components and strategies to be included in the programme and consensus was set at 70% or more for an item to be included in the programme

3.5 Ethics

Permission and ethics clearance was sought from Senate research committee at the University of the Western Cape (UWC) (Appendix 1). Further permission was sought from the Quad-Para association of South Africa (QASA) (Appendix 2a). To ensure the protection of personal information as stipulated in the Protection of Personal Information (POPI) act (No 4 of 2013) (Buys, 2017), the organisation sent out invitations to individuals on their database to participate in the study. Once consent was given by the individuals with a TSCI, the researcher sent out information sheets and contact details to those willing to participate. The study was conducted according to the ethics practices pertaining to the human subjects as specified by the Faculty of Community and Health Sciences research ethic committee. The purpose of the study was clearly explained by the researcher to the participants (Appendix 3a, 3b, 3c). Written informed consent was signed by all participants in an information sheet (Appendix 4a, 4b, 4c). Participation in the study was voluntary. The participants were informed of their rights to withdraw from the study at any time without any consequences. Participants were treated with respect and dignity. The consent forms, information sheets and questionnaires were available in English, Afrikaans and Xhosa. Identification codes using numbers were used on data forms to ensure anonymity. During the reporting of qualitative results, pseudonyms were used to disguise the true identity of the participants. Information obtained from the participants was for the study only and it will be handled with confidentiality. Pseudonyms will be used to protect participant's identities when the results are published. Completed questionnaires, Transcripts and memoranda were also kept in a locked cabinet and no unauthorised persons have an access to the data. Captured data from the quantitative phase, audio-recording interviews, transcripts are stored in the password protected file on the researcher's computer. The finding of the study will be made available to all the relevant stakeholders.

3. 6 Summary of the chapter

This chapter provided an overview of the methods used to reach the overall aim of the study. A brief description of research setting, each phase's aim, study design and methods, study sample, Data collection procedures and analysis were provided. Cape Metropolitan Area of the Western Cape Province, South Africa was the setting of this study. Mix methods employing both qualitative and quantitative were used to collect the data. Self- administered/interview-administered questionnaire was used to collect the data that determined baseline information regarding reintegration of individuals of a TSCI into their communities. Individual in-depth tape recorded interviews were conducted to explore multiple stakeholders' views regarding what is needed for the optimal community reintegration of individuals with a TSCI. A scoping review was conducted to review the programmes addressing community reintegration of individuals of a TSCI. A Delphi study was conducted to reach consensus on the components and strategies to be included in the community reintegration programme. The results of quantitative and qualitative analysis are presented in chapter 4 and 5. The results of scoping review are presented in chapter 6. Chapter 7 provides integrated discussion of the results of chapters 4,5 & 6. The results of the Delphi study are outlined in chapter 8.

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Chapter Four

Self- reported community reintegration after a traumatic spinal cord injury

"I can do everything through him who gives me strength "

Philippians 4:13

Abstract

Background: Successful community reintegration following spinal cord injury is considered an essential goal of rehabilitation as this has been positively associated with self-esteem, life satisfaction and quality of life.

Objective: To determine baseline information regarding reintegration into communities after sustaining a TSCI in the Cape Metropolitan Area, Western Cape province, South Africa.

Methods: A quantitative cross-sectional survey was conducted using a self-administered questionnaire that included the following scales: Sydney Psychosocial Reintegration Scale (SPRS-2), Community Reintegration Measure (CIM), Moorong Self-efficacy (MSES) and Spinal Cord Injury Quality of Life Questionnaire (SCIQOL). Descriptive statistics and frequency counts were used to summarize the sociodemographic data of the study sample. T-tests, one-way analysis of variance (ANOVA) and chi-square tests were used to examine sociodemographic and injury factor differences within the sample. Alpha level was set at 0.05.

Results: The overall sample consisted of 108 individuals with a TSCI ranging from 19-71 years old (M= 37.2; SD = 12.2) who were living in the community and were between 1 and 35 years after the injury (M= 10.24; SD= 9.1). The total mean scores for both psychosocial and perceived community reintegration were 27.87 and 32.81 respectively. Employment was found to be a significant variable influencing community reintegration following a TSCI, and a positive strong correlation was found between community reintegration, self-efficacy and quality of life.

Conclusion: Participants scored moderately low in both psychosocial and perceived community reintegration suggesting that there is a great need to develop interventions to better reintegrate individuals with a TSCI into their communities following the injury.

4.1 Introduction

Spinal Cord Injury (SCI) is a devastating condition often affecting young and healthy individuals around the world. According to Singh et al., (2014), the global estimate of SCI ranges from 10 to 80 per million populations. A high incidence rate of a TSCI has also been reported in South Africa. Joseph et al., (2015) reported the first population based incidence rate of 75.6 per million population resulting mainly from violence- related causes that was approximately 60% of all cases, transport related causes of 26% and falls t accounted 12% of all cases. SCI conditions not only creates enormous physical and emotional suffering to individuals but also is a significant financial burden to families and society at large (Pickelsimer et al., (2010); Ackery et al., (2004).

Due to the severity of a TSCI, the impact on personal, bio-psychosocial, short and long term socio-economic are tremendous. Both the WHO and ISCOS echoed that SCI has significant consequences at an individual and societal levels (WHO & ISCOS, 2013). Following a SCI, the ability to participate in meaningful life roles and activities in and outside the home can change and diminish significantly (Whiteneck et al., 2004). Participation in work, leisure and sporting activities greatly decrease with an accompanying increase in time spent on individual home-based occupations such as reading, watching television and listening to the radio that consequently leads to social isolation (Barclay et al., 2011).

People living with a TSCI have to cope with several challenges. The main challenge starts when they return home from rehabilitation centres and they have to reintegrate back into their families and participate in their communities (Mothabeng, 2011). Long term rehabilitation of the persons with SCI is therefore, essential in order to help them return to normal function or

as close as possible (Maclachlan, 2012). Rehabilitation includes all measures aimed at reducing the impact of disabling conditions and at enabling the disabled to achieve the degree of self-care and social integration. According to the World Health Organization (WHO), rehabilitation aims not only at training disabled persons to adapt to their environment but also at intervening in their immediate environment and society as a whole in order to facilitate their reintegration. It helps them adjust to life after SCI by equipping them and their families with the skills and resources required for living in the community (WHO, 2001).

A definition pertinent to community reintegration varies within literature. However, common factors include relationships with others, independence in activities of daily living and spending time meaningfully (Mc Coll, Carlson, Johnston, Mines, Shue & Davies, 1998). Reintegration according to Willer et al., (1993) is a multidimensional construct including reintegration into home life setting, into social networks and integration into productive services such as employment, school and volunteer work. The authors further provided definitions on the three different levels of reintegration separately. They referred to home reintegration as the active participation of an individual in the operation of the residence including activities such as doing groceries, preparing meals doing house hold work, caring for children and planning for social gatherings in homes. Social reintegration is referred to as activities that require participation outside the residence such as shopping, recreation or leisure activities while productive reintegration is referred to as education, employment and vocational activities as well as ability to travel alone (Willer et al.,1993).

A study conducted by Joseph et al., (2015) in the Cape Metropolitan Area found that community reintegration is also greatly hampered in South Africa. Environmental factors such as infrastructures that are inaccessible, lack of adequate transport and negative attitudes of general population were reported to be the main barriers to community life involvement after the injury. In addition to the environmental factors, personal factors such as age, gender, ethnicity, educational status, employment status as well as residential local have been also found to influence community integration in the Tshwane Metropolitan Area (Mothabeng, 2011).

Despite being considered an important rehabilitation outcome, a paucity of information regarding how best to facilitate community reintegration following a TSCI still exist in South Africa. Minnes et al., (2003) recommended that more than one measure of community reintegration be used to include both subjective perception and objective indicators in order to address the complexity of community reintegration. Objectively, community reintegration can be described as how often and how independently the person can participate in daily activities such as: home activities, social activities, and productive activities. Subjective community reintegration on the other hand can be described as the person's perception of their ability to reintegrate into their communities and not the actual participation. Evidence also exist that self-efficacy can influence both objective and subjective community reintegration as individuals with SCI may experience functional limitations and societal barriers that can affect the belief they have in their ability to perform every day activities and reach desired community reintegration outcomes (Miller, 2009). In addition, low self-efficacy in individuals with SCI have also been associated with lower quality of life (Middleton et al., 2007). Middleton used a cross-sectional study with multiple independent measure to explore the relationship between QOL and self-efficacy in over one hundred individuals with SCI and the results indicated a

significant relation between self-efficacy and QOL ($p<0.001$) with lower self-efficacy related to low QOL. The main aim of this study is therefore to report on the investigation of self-reported objective and subjective community reintegration following a TSCI in the Cape Metropolitan Area, Western Cape, South Africa. In order to address this complexity, the psychosocial, perceived community reintegration, self- efficacy and quality of life of the individuals with a TSCI were all measured.

4. 2 Materials and Methods

Design: The study was cross- sectional in nature and used standardized instruments to examine self-reported community integration.

Population and sampling: Recruitment of the participants took place in the Cape Metropolitan Area of the Western Cape, South Africa. Strategies included invitations through the Quad-Para Association of South Africa (QASA), and word- of- mouth (snowball technique). The QASA offers training, housing and support to individuals who sustained a TSCI in South Africa. QASA has offices in various provinces within the country. In the Western Cape, there were approximately 300 individuals listed on the QASA database in the year 2015. To calculate a sample size for this study, this number was used as a guide line and the Yamane formula was used to calculate a sample size. Yamane provides a simplified formula to calculate sample sizes (Israel, 1992).

$$n = \frac{N}{1 + N(e)_2} = \frac{300}{1 + 300(.05)_2} = 170$$

Where *n* is the sample size, *N* is the population size and *e* is the level of precision.

Therefore, approximately 170 participants were approached for participation and 108 filled and returned the questionnaire thus yielding 64% response rate.

Inclusion criteria: Participants were included if they met the following inclusion criteria that was set out for the study: (1) above 18 years of age (2), residing in the Cape Metropolitan Area, South Africa, (3) Medical diagnosis of a TSCI, (4) current wheelchair use, all self-reported.

Measurement instruments: Data was collected with self-administered/interview-administered questionnaire that includes the Sydney Psychosocial Reintegration Scale (SPRS-2), Community Integration Measure (CIM), the Moorong Self- Efficacy Scale (MSES) and the Spinal Cord Injury Quality of Life (SCIQOL). The scales included in the questionnaire are described below.

The Sydney Psychosocial Reintegration Scale: This is a 12 items instrument that measured psychosocial reintegration of the study sample. SPRS-2 was initially designed to measure psychosocial reintegration after traumatic brain injury (TBI) targeting three domains namely: (a) occupational activities (OA) e.g. "*how do you rate your work/study skills?*", (b) interpersonal relationship (IR) e.g. "*how do you rate your relationship with other family members?*" and (c) living skills (LS) e.g "*how do you rate your social skills and behaviour in the public?"*. The SPRS-2 is a 5- point scale developed from the SPRS instrument that originally used a 7- point rating scale. The changes were made in response to user feedback with the aim of improving ease of administration and completion (Tate *et al*; 2011). Scores range from 0-16 for each domain and 0-48 for SPRS-2 total score with higher score indicating better psychosocial functioning. The SPRS-2 has shown good psychometric properties within TBI population and its' reliability, validity and sensitivity to change while measuring community reintegration of people with SCI has also been tested in comparison with Craig handicap assessment and reporting technique (CHART) and the SPRS-2 has shown to be an

instrument with greater sensitivity to change and with overall less ceiling effects compared to CHART (Tate et al, 2011).

The Community Integration Measure*:* this is a client centred 10 item scale of participation that was used to measures the sample's sense of belonging in the community. Responses are made on a 5- point rating scale from 5 (*always agree*) to 1 (*always disagree*). e.g. "*I like where am living now*" and "*I have something to do in my community during part of my day that is useful and productive*". The CIM results in a single summary score (range 10-50), with higher score indicating better reintegration. Construct validity of the CIM has been established among several impairment groups. Internal constancy is excellent (Cronbach alpha = 0.85) (Lysack et al., 2007; Reistetter, Spencer, Trujillo, & Abreu, 2005). Furthermore, its reliability, validity and sensitivity to change while measuring community integration with individuals of SCI has also been tested in comparison with CHART and it was found to be internally consistent (De Wolf et al., 2010).

The Moorong Self-Efficacy**:** this is a spinal cord specific measure of self- efficacy that assesses confidence in performing daily activities (Middleton et al., 2003). It is composed of 16 items and two subscales namely: (a) daily activity e.g. "*I can participate as an active member of the house hold*" and (b) social functioning e.g. "*I can enjoy spending time with my friends*". Each item is rated on a 5 point Likert-type scale ranging from 1 (*very uncertain*) and 5 (*very certain*). The total score range from 16 to 80, with higher scores indicating higher levels of self - efficacy. The scale has a good internal consistency and test- retest reliability of 0.74 (Miller, 2009).

The Spinal Cord Injury Quality of Life*:* this is a 3 item (domains) instrument that was used to measure the sample's quality of life. The three domains measured by the SCIQOL instrument includes: General quality of life, physical health and psychological health. Responses are

scored ranging from 0-10 with 0 meaning completely disagree and 10 meaning completely agree. SCIQOL has not yet undergone psychometric testing but its use is recommended based on experience with other similar instruments that request rating subjective states or experiences on a 0-10 numeric rating scale (Charlifue et al., 2012).

Reliability and Validity of the instrument

Reliability is the ability of an assessment instrument to give the result if repeated under the same conditions (Bless & Higson-Smit, 2000), while validity is the capacity of the assessment instrument to measure what is intended to measure (Silverman, 2000). Validity is one of the most important criteria by which quantitative instruments' adequacy is evaluated (Polit, Beck & Hungler, 2001). To ensure validity of the instrument, the subsections were adopted from previous questionnaires used in the similar studies and which has been tested for their validity, reliability and sensitive to change while measuring community reintegration of individual with traumatic spinal cord injury (Charlifue et al., 2012; Tate et al, 2012; De Wolf et al., 2010; Miller, 2009, Lysack et al., 2007; Reistetter et al., 2005). In addition, a draft of the questionnaire for individuals with traumatic spinal cord injury with all sub-scales was translated into isiXhosa, and Afrikaans by independent translator fluent in respective language. It was then back translated into English by a linguist in Afrikaans and isiXhosa respectively. Furthermore, translated questionnaires were administered to sub-sample of a TSCI individuals as a pilot study. This was done to assess the face validity and applicability of all items for this population and the time it would take to complete. The time taken to complete the questionnaire by individuals with a TSCI ranged between 10 and 20 minutes. The results of the pilot study indicated that the instrument was clear, understandable, relevant to the population and was easy to be used by the clients with a TSCI.

Data analysis: Data was captured and analysed using SPSS version 24. Data collected were coded, cleaned and checked for errors such as coding mistakes, impossible responses and missing data. Descriptive statistics was employed to summarize the demographic data and it is presented using frequency tables and expressed as percentages, means and standard deviation (SD). Continuous variables such as age and survival time were expressed as means and (SD). Categorical variables such as gender, race, marital status, level of education, employment status, accommodation, and level of the injury as well as causes of the injury were expressed as frequencies and percentages. Inferential statistical analysis was used to determine the association between socio- demographic characteristics such as: gender, age, level of the injury, marital status, accommodation, employment status and psychosocial, community reintegration, quality of life as well as self- efficacy of individuals with a TSCI. Chi- square test, student t-tests and one-way analysis of variance (ANOVA) was used to determine the relationships between different variables. Alpha level was set at 0.05. Furthermore, regression analysis using Pearson's r was done to determine the correlation coefficient (relationships) between CIM, SPRS-2, MSES and QOL.

4.3 Results

This study reports the complexity of community reintegration following a TSCI. Both objective (measured by SPRS-2) and subjective (measured by CIM) views of community reintegration are reported. In addition, self-efficacy (measured by MSES) and quality of life (measured by SCIQOL) in relation to the concept of community reintegration are reported too.

4.3.1 Description of the study sample

The overall sample consisted of 108 individuals with a TSCI ranging from 19-71 years old (M= 37.2; SD = 12.2) who were living in communities in the Cape Metropolitan Area, Western Cape Province, South Africa and were between 1 and 35 years after the injury (M= 10.24; SD= 9.1). The majority of the sample were males 77.8% (n=84) and 22.2% were females (n= 24). Almost half (45.4%, n= 49) were black and approximately two thirds (62%, n= 67) were unemployed. Regarding the level of the injury, the majority of participants (58.3%, n= 63) were classified as paraplegic, while 41.7%, n= 45 as tetra/ quadriplegic. The cause of injury was mostly motor vehicle accidents (43.5%, n=47) followed by violence related causes (38%, n=41). Table 4.1 summarises the study sample characteristics.

As indicated in Table 4.1, male participants had a significantly higher mean age compared to their female counter parts. A statistically significant difference was also observed between gender, time since the injury and race at $p< 0.05$. No statistically significant differences were observed between gender and the rest of demographic variables.

Table 4.1 Characteristic of the study sample (n= 108)

Variables	Males (n=84)	Females (n= 24)	P-Value	Total (n=108)
Mean Age (SD) *	38.38(12.8)	33.29(8.9)	**0.002**	37.2 (12.2)
Length of time since injury (SD)*	11.20 (9.7)	6.88 (6.2)	**0.011**	10.24 (9.2)
	Frequency (%)	**Frequency (%)**		**Frequency (%)**
Race*			**0.002**	
Black	41(48.8)	8 (33.3)		49 (45.4)
Coloured	18 (58.3)	14 (21.4)		32 (29.6)
White	25 (29.8)	2 (8.3)		27 (25.0)
Marital Status			0.378	
Single	70 (79.5)	18 (20.5)		88 (81.5)
Married	14 (70.0)	6 (30.0)		20 (18.5)
Level of Education			0.105	
Completed Primary	6 (7.1)	3 (12.5)		9 (8.3)
Some Secondary	26 (31.0)	5 (20.8)		31(28.7)
Completed Secondary	21(25.0)	7 (29.2)		28 (25.9)
Post Matric Diploma	13 (15.5)	8 (33.8)		21(19.4)
Tertiary	18 (21.4)	1(4.2)		19 (17.6)
Employment Status			0.958	
Employed	32 (38.1)	9 (37.5)		41(38.0)
Full Time	*20 (62.5)*	*5 (55.6)*		*25 (61.0)*
Part Time	*12 (37.5)*	*4 (44.4)*		*16 (39.0)*
Unemployed	52 (61.9)	15 (62.5)		67 (62.0)
Disability Grant	*36 (69.2)*	*12 (80.0)*		*48 (71.6)*
Student	*7(13.5)*	*3(20.0)*		*10(14.9)*
Retired	*9(17.3)*	*0 (0.0)*		*9 (13.4)*

Table 4.2 Continued

Variables	Males (n=84) Frequency (%)	Females (n= 24) Frequency (%)	P-Value	Total (n=108) Frequency (%)
Accommodation			0.062	
House	34 (40.5)	16 (66.7)		50 (46.3)
Nursing Home	26 (31.0)	3 (12.5)		29 (26.9)
Informal Dwelling/ Shack	24(28.6)	5 (20.8)		29 (26.9)
Level of Injury			0.159	
Paraplegia	46 (54.8)	17 (70.8)		63 (58.3)
Tetra/Quadriplegia	36 (45.2)	7 (29.2)		45 (41.3)
Cause of Injury			0.055	
MVA	32 (38.1)	15 (62.5)		47(43.5)
Violence	34 (40.5)	7 (29.2)		41(38.0)
Sports	14 (16.7)	0 (0.0)		14 (13.0)
Fall	4 (4.8)	2 (8.3)		6 (5.6)

***** Statistically significant at $p < 0.05$.

4.3.2 Psychosocial reintegration

Psychosocial reintegration of the study sample as measured by the SPRS-2 consist of three domains namely: occupational activity (OA), interpersonal relationship (IR) and living skills (LS). The overall total mean score for SPRS-2 was: (M=27.87, SD= 13.4). The means of respective domains were: OA (M=8.62, SD= 4.8., IR (M= 9.80, SD= 5.1)., LS (M= 9.45, SD= 4.9).

The relationship between the SPRS-2 overall mean score, the three different domains scores and selected variables was examined and the results are presented in table 4.2

Table 4.2 Relationship between SPRS-2 and selected variables

Variables	SPRS-2 Mean (SD)	p-value	OA Mean (SD)	P-value	IR Mean (SD)	P-value	LS Mean (SD)	P-value
Gender		0.132		0.203		0.212		0.137
Male	28.90(13.5)		8.94(4.8)		10.13(5.4)		9.83(4.5)	
Female	24.25(12.4)		7.50(5.3)		8.63(4.5)		8.13(4.5)	
Race*		**0.001**		**0.000**		**0.008**		**0.011**
Black	23.08(12.6)		6.88(4.5)		8.24(5.3)		7.96(5.1)	
Coloured	29.31(14.5)		8.72(5.1)		10.38(5.6)		10.22(5.3)	
White	34.85(9.7)		11.67(3.9)		11.93(3.7)		11.26(3.7)	
Employment*		**0.000**		**0.000**		**0.004**		**0.004**
Employed	33.63(11.9)		10.95(4.5)		11.51(4.3)		11.17(4.5)	
Unemployed	24.34(13.1)		7.19(4.4)		8.75(5.5)		8.40(5.0)	
Accommodation*		**0.001**		**0.005**		**0.041**		**0.000**
House	31.98(11.4)		10.04(4.7)		10.82(4.5)		11.12(4.2)	
Nursing home	28.41(15.1)		8.4(4.6)		10.03(6.1)		9.97(5.7)	
Informal Dwelling	20.24(11.8)		6.38(4.5)		7.79(5.0)		6.07(3.9)	

SPRS-2: Sydney Psychosocial Reintegration Scare, OA: Occupational Activities, IR: Interpersonal Relationships, LS: Living Skills

*****statistically significant at $p<0.05$

A statistically significant difference was observed for the total SPRS-2, all 3 domains scores, race, employment status and accommodation. Black participants had a significantly lower mean score for all the domains compared to those classified as Coloureds and Whites ($p< 0.05$). Those unemployed also had a significantly lower mean score for the all domains compared to

those employed ($p < 0.05$) and those living in informal dwellings/shacks had a significantly lower mean score compared to those living in house and nursing homes ($p<0.05$).

One way between analysis of variance (ANOVA) was done to determine the impact of race on the level of psychosocial reintegration. There was a statistically significant difference in SPRS-2 scores for the different race groups: $F(2, 105) = 7.9$, $p = .001$. Post- hoc comparison using the turkey HSD test indicated that the mean score for Black participants ($M=23.08$, $SD= 12.6$) was significantly lower compared to White participants ($M=34.85$, $SD=9.7$). Coloured participants ($M= 29.31$, $SD=14.5$) did not differ significantly from either Black or White participants. Despite reaching statistical significance, the actual difference in mean scores was quite small. This was determined by the effect size calculated using eta squared formula (Cohen, 1988, P. 284-7) that was .01. According to Cohen's guidelines, .01 or 1% of variance is considered a small effect size, .06 or 6% of variance is considered a medium effect size whereas .138 or 13.8% of variance is considered as large effect size.

To clarify where the difference occurred between race and SPRS-2 different domains, Post-hoc comparisons using Tukey HSD test was done and the test indicated that Black participants significantly differed with Whites in all domains (OA, IR, LS). Coloured participants significantly differed with Whites on the OA domain and no significant differences was observed between Coloureds and Blacks in all domains.

One way between groups analysis of variance was also conducted to determine the impact of residential area on psycho- social reintegration. Participants were residing in three different residential settings (house, nursing homes and informal dwelling). There was a statistically significant difference at $p<.05$ level in SPRS-2 score for the three different residential settings: $F(2,105) = 8.1$, $p=.001$. Post-hoc comparison using Tukey HSD test indicated that the mean score for individuals that lived in a house (M=31.98, SD=11.4) was significantly higher compared to individuals that lived in informal dwelling (M= 20.24, SD= 11.8). Individuals that lived in nursing homes (M= 28.41, SD= 15.1) also had a significantly higher mean score compared to individuals that lived in informal dwelling (M=20.24, SD=11.8). No statistically significant difference was observed between individuals that lived in a house (M=31.98, SD=11.4) and those that lived in nursing homes (M=28.41, SD= 15.1). Post- hoc comparisons using Tukey HSD test was done to further clarify where the differences occurred between residential setting and different domains (OA, IR, LS) and the test indicated that individuals who lived in a house significantly differed with individuals who lived in informal dwelling in all domains. There was no statistically difference between individual who lived in a house and those that lived in a nursing home in all domains. However, the LS domain was statistically different between individuals that lived in a nursing home and those that lived in informal dwellings.

4.3.3 Perceived community reintegration

The perceived community reintegration of the study sample as measured by the CIM is summarised in Table 4.3

Items are arranged in a descending manner from the highest to the lowest scores

Table 4.3 Mean Scores of CIM individual items in descending order (n=108)

Items	Mean	S.D
I know a number of people in this community well enough to say hello and they say hello back	3.74	1.4
I know my way around this community	3.63	1.5
There are people I feel close to in this community	3.63	1.4
I know the rules in this community and I can fit in with them	3.60	1.4
I like where I am living now	3.47	1.5
I feel like I am accepted in this community	3.44	1.5
There are things that I can do in this community for fun and in my free time	3.33	1.4
I can be independent in this community	3.33	1.5
I have something to do in this community During part of my day that is useful and productive	3.13	1.4
I feel like part of this community, like I belong here	3.13	1.5
The overall CIM total score	**32.81**	**13.9**

The three items endorsed the most were: CIM- 8 “I know people well enough to say hello and having them say hello back” (M= 3.74, SD= 1.5), CIM-2, “I know my way around the community” (M= 3.63, SD= 1.5), and CIM- 7 “there are people I feel close to in the community” (M= 3.63, SD= 1.5). The three CIM items with the lowest scores were: CIM-5 “I

can be independent in the community" (M= 3.33, SD= 1.6), CIM -1 "I feel like part of the community" (M= 3.13, SD= 1.6) and CIM-10 "I have something useful/productive to do in the community" (M= 3.13, SD= 1.5).

Despite the fact that the total CIM score is highly skewed (see Figure 4.1) with 40% of the study participants reporting a CIM score of 41 or higher (out of a possible 50), The overall mean score was 32.81 (SD=13.9). Recalling that a score of 4.0 on CIM indicates "agreement" and 5 indicates "strong agreement", it is evident that the sample generally rated their community reintegration as slightly low.

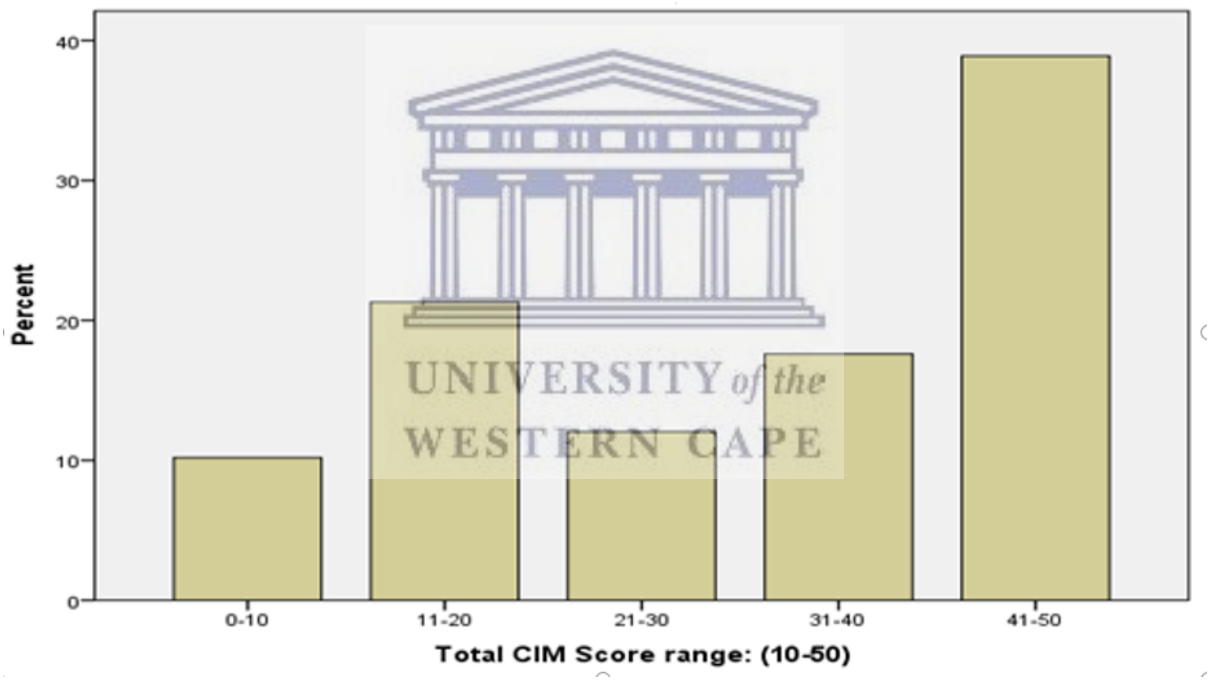

Figure 4.1 Distribution of Total CIM Score

To clarify the distribution of CIM scores further, a model of CIM score was created using a cut off- point score of 40 (CIM <=39 versus =>40) and the results (Figure 4.2) indicated that the biggest number of participants (53.7%, n=58) had total score of less than 39 and 46.3% (n=50) scored more than 40. This model has the advantage that the two categories are easily interpretable (with <=39 including those participants who strongly disagree, disagree and neutral and => 40 indicating those who agree and strongly agree.

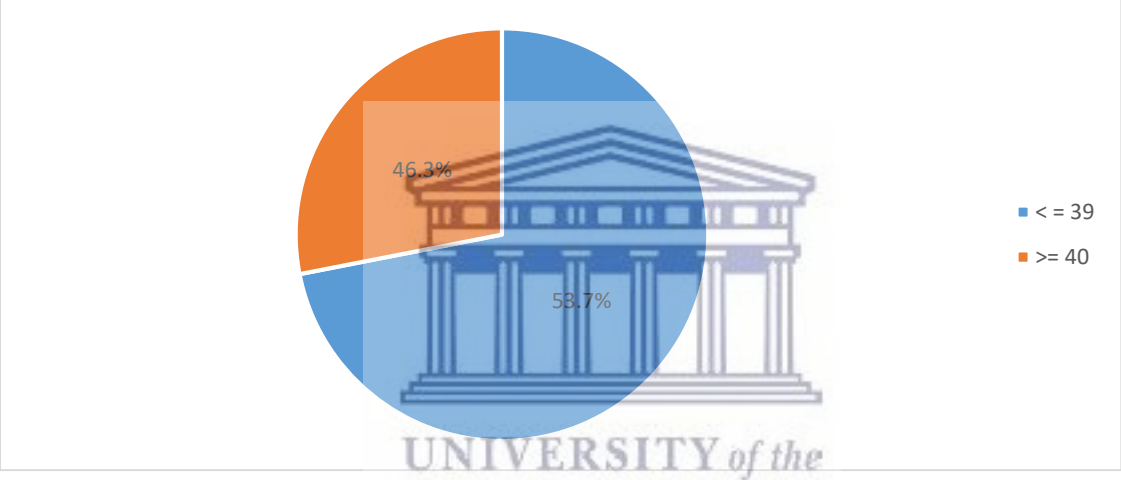

Figure 4.2 Distribution of CIM Scores (CIM: <39 versus > 40)

The overall CIM score was further examined for selected variables and the results are presented in table 4.4.

Table 4.4 Relationship between CIM score and selected variables

Variables	CIM Mean Score (SD)	P- Value
Survival time		0.604
1-5	30.06 (14.4)	
6-10	29.62 (13.6)	
11-15	38.00 (12.5)	
16 and above	36.85 (12.6)	
Age		0.142
15-29	28.58 (14.9)	
30-44	34.26 (12.3)	
45-59	36.50 (13.3)	
60 and above	34.15 (13.9)	
Gender*		**0.013**
Male	34.56 (13.0)	
Female	26.67 (15.4)	
Race		0.225
Black	30. 86 (14.2)	
Coloured	32. 59 (14.8)	
White	36.59 (11.8)	
Employment Status*		**0.003**
Employed	37.76 (13.4)	
Unemployed	29. 78 (13.4)	
Accommodation*		**0.005**
House	35.58 (12.6)	
Nursing Home	35.10 (12.7)	
Informal dwelling	25.72 (15.1)	
Table 4.4 continued		
Level of Injury*		**0.008**
Paraplegia	29.84 (13.8)	
Tetra/ Quadriplegia	36.96 (13.0)	
Marital Status		0.435
Single	32.31(13.7)	
Married	35.00 (14.9)	

*statistically significant at $p<0.05$

A statistically significant difference (Table 4.4) was found between the overall mean CIM score, gender, employment status, accommodation and level of the injury at level of P< 0.05.

Male participants had a significantly higher mean score compared to females, individuals who were employed had a significantly higher mean score compared to unemployed and those that were classified as tetra/quadriplegia had a significantly a higher score compared to those that were classified as quadriplegia (p< 0.05).

One way between groups analysis of variance (ANOVA) was conducted to further clarify the impact of residence on community reintegration as measured by community reintegration measure (CIM). Participants were residing in three different accommodation setting (house, nursing home, and informal dwelling). There was a statistically significant difference at P< 0.05 level in total CIM scores for the three different settings: F (2,105) = 5.6, P= .005. Post-hoc comparisons using the Turkey HSD test indicated that the mean score for individuals that lived in the house (35.58, SD=12.6) was significantly higher from that of individuals who lived in informal dwelling (25.72, SD=15.1). Individuals that lived in the nursing homes (35.10, SD=12.7) also significantly differed from those that lived in the informal dwellings. No statistically difference was observed between individuals that lived in the house and those that lived in nursing home.

4.3.4 Self-efficacy of the participants

Self-efficacy of the study sample as measured by MESES consist of two different factors namely daily activity (DA) and social functioning (SF). The overall total mean score for MESES was: (M= 55.06, SD=15). The means scores of the factors were: DA (M= 26.63, SD= 8.0)., SF (M= 28.44, SD= 8.4).

The overall self-efficacy means score and two factors (DA and SF) were also examined for selected variables and the results are presented in Table 4.5

A statistically significant difference was found between the total MSES score, gender and employment status. Female participants had significantly lower mean score compare to males and those who were unemployed had significantly lower mean score compare to those that were employed $p<0.05$. There was also a statistically significant difference between the Daily Activity factor (DA) and accommodation $p<0.05$.

Furthermore, a statistically significant difference was found between the DA, SF scores, gender and employment. Female participants had a significantly lower total mean score (MESES) and factors (DA & SF) when compared to males $p<0.05$. Participants that were unemployed had a significantly lower total mean score (MESES) and factors (DA& SF) when compared to those participants that were employed $p<0.05$.

A statistically significant difference was also observed between the type of accommodation and the DA factor. Individuals who lived in informal dwelling/shack had a significantly lower mean DA score compared to those living in a house or nursing home $p<0.05$.

Table 4.5 Relationship between Self- efficacy and selected variables

Variables	MSES Total Mean (SD)	P-Value	DA Mean (SD)	P- Value	SF Mean (SD)	P-Value
Gender*		**0.002**		**0.000**		**0.000**
Male	58.00 (13.1)		27.92 (7.6)		30.08 (7.4)	
Female	44.79 (16.7)		22.13 (7.8)		22.67 (9.8)	
Race		0.250		0.546		0.165
Black	53.00 (15.5)		25.86 (8.7)		27.14 (8.7)	
Coloured	54.94 (15.3)		26.69 (8.1)		28.25 (8.8)	
White	58.96 (13.1)		27.96 (8.0)		31.00 (7.5)	
Employment*		**0.002**		**0.011**		**0.002**
Employed	60.66 (14.2)		29.10 (7.6)		31.56 (7.3)	
Unemployed	51.64 (14.4)		25.12 (7.9)		26.52 (8.7)	
Accommodation		0.055		**0.040***		0.168
House	57.46 (14.1)		27.78 (7.5)		29.68 (7.6)	
Nursing Home	56.59 (12.6)		27.83 (6.3)		28.76 (9.2)	
Informal Dwelling	49.41 (17.4)		23.45 (9.5)		25.97 (10.0)	
Level of the Injury		0.639		0.708		0.239
Paraplegia	54.49 (14.7)		26.87 (7.8)		27.62 (7.9)	
Quadriplegia	55.87 (15.5)		26.29 (8.3)		29.58 (9.3)	

*statistically significant at $p<0.05$

4.3.5 Quality of life

Quality of life measured by SCIQOL consist of three different domains namely physical health, psychosocial health and Life as a whole. The overall QOL score was: (M=17.47, SD=6.61). The mean scores of each domain were: physical health (M=5.81, SD= 2.4); psychosocial health (M= 5.97, SD= 2.6); life as whole (M= 5.69, SD=2.1). The relationship between the overall QOL and selected variables was also examined and the results are presented in Table 4.6

Gender, employment status, accommodation and the level of injury were significantly associated with QOL in this study. Female participants had significantly lower mean scores compared to males. Individuals that were unemployed had significantly lower scores compared to those that were employed. Participants who lived in informal dwelling/shack had lower mean scores compared to those that lived in a house or nursing home, and individuals that were classified as paraplegic had lower mean scores compared to those that were classified as tetra/quadriplegic $P < 0.05$.

One- way between groups analysis of variance (ANOVA) was conducted to further clarify the impact of accommodation type on quality of life. There was a statistically significant difference at the $p<0.05$ level in QOL scores for the three different types of accommodation: $F (2,105) =5.1$, $p< .007$. Post-hoc comparisons using the Turkey HSD test indicated that the mean score for individuals that lived in a nursing home (M= 20.48, SD= 7.03) was significantly different from the mean score for individuals that lived in informal dwelling/shack (M= 15.21, SD= 5.97). Individuals that lived in a house did not differ significantly from either those that lived in informal dwelling or a nursing home.

Table 4.6 Relationship between QOL and selected variables

Variables	QOL Mean Score (SD)	P- Value
Gender*		**0.000**
Male	18.58 (6.6)	
Female	13.58 (5.4)	
Race		0.106
Black	16.14 (5.9)	
Coloured	17.84 (5.4)	
White	19.44 (6.5)	
Employment Status*		**0.027**
Employed	19.27 (6.6)	
Unemployed	16.37 (6.5)	
Accommodation*		**0.007**
House	17.04 (6.2)	
Nursing Home	20.48 (7.1)	
Informal dwelling	15.21 (6.0)	
Level of Injury*		**0.019**
Paraplegia	16.16 (5.7)	
Tetra/ Quadriplegia	19.31(7.5)	

*statistically significant at $p<0.05$

Further analysis was done to determine relationship (correlation coefficients) between CIM, SPRS-2, QOL and Self- efficacy and the results are summarised in table 4.7.

Table 4.7 Correlation between CIM, SPRS-2, QOL and Self-Efficacy

		Perceived community Reintegration
Psychosocial integration		
	Pearson correlation	.348
	Sig. (2-tailed)	000
Quality of life		
	Pearson correlation	.602
	Sig. (2-tailed)	000
Self- efficacy		
	Pearson correlation	.640
	Sig. (2-tailed)	000

A significant strong correlation was found between CIM, Self- Efficacy and QOL (Pearson's r=.640 and .602 respectively) $P < 0.01$. There was also a significant but weak correlation between CIM and SPRS-2 (Pearson's r= .348) $P< 0.01$.

4.4 Discussion

Reintegration into communities following disability is a complex phenomenon that requires the measurement of more than one aspect. Through the multidimensional approach, this study successfully identified baseline information regarding reintegration of individuals with a TSCI into their communities. As suggested by Minnes et al., (2003), both objective indicators (measured by SPRS-2) and subjective perceptions (measured by CIM) of individuals with a TSCI regarding their reintegration into communities following the injury were reported. In addition, self-efficacy and quality of life were also measured as evidence exist that self-efficacy can influence both objective and subjective community reintegration and that low self-efficacy among individuals with SCI may be associated with lower quality of life (Miller et al., 2009; Middleton et al., 2007).

It has been reported in literature that the ability to participate in meaningful life roles and activities outside the home can change and diminish significantly following a SCI (Whiteneck et al., 2004; Brown, Gordon, Spielman &Haddad, 2002). According to Barclay et al., (2016), participation in work, leisure and sporting activities greatly decreases with an accompanying increase in time spent on individuals' home- based occupations such reading, watching television and listening to the radio subsequently leading to social isolation. Similarly, the measured psychosocial and community reintegration in this study was low. The lowest score of psychosocial reintegration was found to be in occupational activity (OA) and living skills (LS) domains. Tate et al., (2012) also reported a lower OA score compare to the other domains in an Australian study. When the physical limitation of an individuals with a TSCI is considered, this could be clearly understood. However, when considering this particular study sample, 62% indicated unemployment. Therefore, this would be assumed as a clear explanation of the low score on the OA domain.

When comparing the living skills domain with that of Tate et al., (2012), this study reported a much lower mean score. Hypothetically, the differences could be attributed to the different socio-economic settings. Both community travel and accommodation items are captured within this domain and by considering some of the poor neighbourhood conditions in this study (26.9% indicated living in informal dwellings/shacks), this could be a possible explanation for a low score in this domain.

The influence of one's socio-economic surroundings or setting is also evident in the subjective community reintegration measured by the CIM. The total mean score attained in this study (M= 32.81) compares very low against the scores of 42.9 reported by Lysack et al., (2007) in the United States of America. However, when this study's findings are compared to a developing country like Bangladesh where Ahmed et al., (2018) also reported low community reintegration of individuals who sustained a TSCI, the influence of the one's environment to reintegration is even more evident.

Employment was found to be a statistically significant variable that influenced reintegration following a TSCI in this study. Individuals that were employed scored significantly higher on both psychosocial and perceived community reintegration compared to those that were unemployed consistent to the previous reports in the literature. Numerous studies (Ahmed et al., 2018; Carr et al., 2017; Schönherr, Groothoff, Mulder, & Eisma, 2005; Schönherr et al., 2004; Boschen et al., 2003) have previously highlighted that individuals who were employed reported better community reintegration than those that were unemployed. These results also clearly indicate that employment was positively associated with self-efficacy and quality of life. Individuals who were employed had significantly higher mean scores on both self-efficacy

and quality of life. The significant influence of the employment on reintegration, self-efficacy and quality of life found in this study clearly indicate how vocational rehabilitation that addresses the issue of employment is very essential if rehabilitation stakeholders aim to achieve better community reintegration following a TSCI.

The influence of employment could be further seen on the scoring of CIM. It is possible that that individuals were forced to live in the communities that are affordable but not necessarily desirable due to unemployment. This is evident from the item 1 on the CIM that was endorsed the least by the study sample *"I feel like part of the community, like I belong here"*. Because of lack of employment, reintegration was also challenged when people did not have something meaningful and productive to do during the main part of the day in their communities. This can possibly be justified by the item 9 on CIM that was scored the second least by the participants "*I have something to do in this community during part of my day that is useful and productive"*. This is again consistent with the findings of other studies. Lysack et al., (2007) found that lack of something meaningful and productive was the item least endorsed on the CIM 10 items by individuals with SCI in USA. In a broad meta-synthesis of quality of life, Hammell, (2007) found that individuals with SCI needed "to be busy, to have something to wake up to, to explore new opportunities, to be engaged in meaningful activities, to participate and be involved in the meaningful life roles". In Canada, Boschen et al; (2003) found that strong enthusiastic to be productive was expressed by most adults in search of better lives after SCI.

Leach et al., (2010) are of the view that employment is the foundation for social inclusion for both able-bodied and disabled individuals. In South Africa, more particularly in the Western Cape, employment opportunities have been reported as an essential need for reintegration at

the social level (Njoki, Frantz, & Mpofu, 2007). However, in the present study only 38% of the sample were employed. The lower level of education (only 17.6% had tertiary education), absence of adequate vocational training and vocational rehabilitation services for individuals with a TSCI further complicates the process of productive reintegration. Although the Integrated National Disability Strategy for South African National Rehabilitation policy (2000) identified vocational rehabilitation as one of the key components of providing services to those affected with disabilities including those with a TSCI, the present study confirms that this is still an area of rehabilitation that needs a serious attention. The high unemployment rate that was associated with both low reintegration into communities, low self-efficacy and low quality of life in the current study has strong implications on the implementation of vocational rehabilitation services among these individuals.

4.5 Conclusion

Reintegration into communities following a TSCI was relatively low in this study. Employment appears to be a significant variable for reintegration following a TSCI. Individuals that were employed scored higher on both psychosocial, perceived community reintegration, self-efficacy and quality of life. However, it is also evident that finding employment after a TSCI is highly unlikely in South Africa. Therefore, rehabilitation services need to focus on helping individuals with a TSCI to explore meaningful employment opportunities for better community reintegration. Different stakeholders including government departments, business individuals and non- profit organizations should work together on interventions that should enable individuals with a TSCI to integrate back to their communities and help them to (re) enter job market, target to change discriminatory attitudes of the employers and co-workers at the work place as well as they should arrange disability friendly transportation facilities and accommodation appropriate for individuals with a TSCI.

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Chapter Five

Community reintegration for individuals with a traumatic spinal cord injury: Multiple stakeholders' perspectives

"It's not whether you get knocked down, it's whether you get up"

Vince Lombardi, 1913-1970, American football player

Eugene Nizeyimana, Julie Phillips

Abstract

Background: Community reintegration after physical impairment or disability is acquiring/resuming age- gender and culture appropriate, roles/status/activities including independence/interdependence in decision making and productive behaviours performed as part of multivariate relationships with families, friends and others in natural settings.

Objective: The objective of this phase of the study was to explore multiple stakeholders' perspectives regarding community reintegration following a TSCI.

Methods: This was a qualitative design. A total of 28 participants from different stakeholders groups including individuals with a TSCI (n=11), caregivers (n=6), rehabilitation professionals (n=3), members representing disabled people's organizations (n=5), members of Quad-Para association South Africa (n=2), as well as a member representing transportation services of individuals with disabilities (n=1) were interviewed face to face by the principal researcher to explore their views regarding community reintegration following a TSCI.

Results: Thematic analysis identified six (6) major themes and seventeen (17) sub-themes. All themes and sub-themes identified by different stakeholders fall under the participation domain of the ICF. Individuals with a TSCI expressed their experiences in form of barriers and facilitators to reintegration. These were confirmed by other stakeholders in their views for what is needed for an optimal community reintegration.

Conclusion: Multiple stakeholders in this phase of the study provided in-depth descriptions of how reintegration into communities following a TSCI is strongly influenced by various domains that falls within contextual factors of the ICF model including environmental and personal factors.

5.1 Introduction

Community reintegration after physical impairment or disability is acquiring/resuming age-gender and culture appropriate, roles/status/activities including independence/interdependence in decision making and productive behaviours performed as part of multivariate relationships with family, friends and others in natural settings (Dijkers, 1998). This definition of community reintegration corresponds with the participation component of the current International Classification of Functioning Disability and Health (ICF) (WHO, 2001). Because participation is directly related to how people live their lives and integrate into community life, people with disabilities and their substantial others identify participation as one of the most highly valued rehabilitation outcome (Magasi et al., 2009).

The ICF endeavours to incorporate all aspects of human health and health related components of well-being and describes them in terms of health domains and health related domains (WHO, 2001b, P.8). The ICF places those health related domains into two broad categories: (1) Functioning and disability and (2) Contextual factors. Contextual factors refer to the physical, social and attitudinal environment in which people live and conduct their lives. Contextual factors include two components as well namely (1) Environmental factors and (2) Personal factors although the WHO has not entirely determined personal factors to be included in the ICF (Hawkins, 2015). Environmental factors therefore, are the main components of the model at this stage. The environmental factors are conceptualized in the five domains namely: (1) natural environment and human-made changes to environment, (2) products and technology, (3) support and relationships, (4) attitudes and (5) services, systems and policies. The ICF also appeals for each environmental component to be classified as either a facilitator or a barrier to community reintegration. The aim of this phase of the study

was to explore multiple stakeholder's perspectives with regard to community reintegration following a TSCI.

5.2 Methods

5.2.1 Design

The research design refers to overall strategies chosen to integrate the different components of the study in a coherent and logical way ensuring that you will effectively address the research problem (De Vaus, 2001). It constitutes the blueprint for the data collection methods, measurements and data analysis. The design for this phase of the study was a qualitative design to explore multiple stakeholders' perspectives regarding community reintegration of individuals with a TSCI. A qualitative design involves the detailed descriptions and analysis to gain a deep understanding of a phenomena and the meaning given to those phenomena. In this phase of the study, multiple stakeholder's perspectives regarding community reintegration following a TSCI were explored.

5.2.2 Population and sampling

The selection of individuals for qualitative research that would assist the researcher to understand the research problem has been emphasized as an important issue by Creswell (2003). Patton (1990) has described all types of sampling in qualitative research under the umbrella term "purposive sampling". The researcher therefore, decided to approach individuals from different stakeholder groups to participate in this study. These groups included individuals with a traumatic spinal cord injury, caregivers, rehabilitation professionals, and members representing disabled people's organization, members of Quad-Para association of South Africa as well as a member representing transport services of individuals with a disability.

Coyne (1997) described this process of determining the initial sample as the fundamental principle of the purposive sampling.

5.2.3 Characteristics of the study sample

A total of 28 participants from different stakeholder groups participated in this phase of the study. Stakeholders included people with a TSCI that were purposively selected from phase one (n=11), caregivers (n=6), rehabilitation professionals (n=3), members representing disabled people's organizations (n=5), members of Quad-Para association South Africa (n=2), as well as a member representing transportation services of individuals with disabilities (n=1).

Table 5.1 presents characteristics of individuals with a TSCI and pseudonyms are used to disguise the true identities of participants.

Table 5.1 Characteristics of individuals with a TSCI (n=11)

ID	Age	Gender	Race	Residence	Level of Injury	survival time (years)
James	37	Male	Black	Shack	Paraplegia (L2)	14
John	35	Male	Black	House	Paraplegia (T12)	8
Peter	42	Male	Coloured	Nursing Home	Quadriplegia (C7)	14
Mary	35	Female	Black	House	Paraplegia (T11)	9
Mark	27	Male	Coloured	Nursing home	quadriplegia (C8)	9
Tim	64	Male	White	House	Paraplegia (T7)	35
Paul	59	Male	White	Nursing Home	Quadriplegia (C6)	6
Nick	24	Male	White	Nursing Home	Quadriplegia (C7)	6
Ana	28	Female	Coloured	Shack	Paraplegia (T10)	3
Monica	25	Female	Black	Shack	Quadriplegia (C6)	4
Tom	28	Male	Black	Shack	Paraplegia (T12)	3

The characteristics of others stakeholders are outlined in the table 5.2

Table 5.2 Characteristics of other stakeholders (n=17)

ID	Gender	Role
PRDPO1	M	Person representing disabled people's organization
PRDPO2	F	Person representing disabled people's organization
PRDPO3	F	Person representing disabled people's organization
PRDPO4	M	Person representing disabled people's organization
PRDPO5	F	Person representing disabled people's organization
MQASA1	M	Member of Quad-Para association South Africa
MQASA2	M	Member of Quad-Para association South Africa
CG1	F	Caregiver
CG2	F	Caregiver
CG3	F	Caregiver
CG4	M	Caregiver
CG5	F	Caregiver
CG6	F	Caregiver
RP1	M	Rehabilitation professional
RP2	F	Rehabilitation professional
RP3	F	Rehabilitation professional
PRTSID1	F	Person representing transportation services for Individuals with disabilities

PRDPO= Person representing disabled people's organization, MQASA= member of qua-para association South Africa, PRTSID= Person representing transportation services of individuals with disabilities, CG= caregiver, RP= rehabilitation professionals

5.2.4 Data collection methods

Qualitative research seeks to make sense of how the world is seen, understood and experienced from individuals' perspective (Braun & Clarke, 2013). This approach therefore, gave the researcher the opportunity to describe all stakeholders' experiences and views of community reintegration after an individual sustained a TSCI. Individual's in-depth face to face interviews were conducted to explore the experiences of individuals with a TSCI regarding community reintegration and to explore the views of other stakeholders on what is needed for an optimal community reintegration following a TSCI. The interviews were conducted at a venue indicated as suitable by the participants. With the permission of the participants, all interviews were audio-recorded and the participants were encouraged to speak freely.

5.2.4 Data analysis

It is clear from the literature that qualitative data is associated with many assumptions and procedures. Thomas, (2006) and others also associated it with very specific analytic approaches such as discourse analysis (Potter & Wetherall, 1994), grounded theory (Strauss & Corbin, 1998). However, Onwuegbuzie et al., (2009) are of the opinion that transcript-based analysis is the most rigorous method. Patton (1990) also states that qualitative data analysis is inductive because patterns and themes emerge from the data rather than being imposed on them. Thus, the analysis of the interviews started with the transcription of the information from the audiotape recordings to produce manuscripts. A comparison was made with the notes taken during the interviews to verify the accuracy. Familiarization and immersion with the data followed by reading the through the transcripts several time by the researcher. The introduction of themes was an inductive process as the transcripts were read through several times. With an emphasis on the emergence of the ideas and themes. Coding was done as data was marked as

it relates to one or more of the themes. During the evaluation stage of the analysis, broader categories were created and data was examined several times. ICF was used as conceptual framework for the data analysis.

The trustworthiness of qualitative data

The trustworthiness of qualitative research generally is often questioned by positivist, perhaps because their concepts of validity and reliability cannot be addressed in the same way in naturalistic work (Shenton, 2004). To address this issue, Guba (1981) proposes four criteria that should be considered in order to provide trustworthiness by qualitative researchers.

These criteria are: *Credibility* (in preference to internal validity), *transferability* (in preference to external validity or generalisability), *dependability* (in preference to reliability) and *confirmability* (in preference to objectivity). To enhance credibility of the interpreted findings, the interviews were sent back to three selected participants as form of member checking to seek feedback regarding their accuracy (Creswell, 2003). In addition, field notes following each interview and reflexive journal were kept to maximise trustworthiness of the data. Furthermore, the transcribed verbatim draft was given to a colleague who is experienced in spinal cord injury rehabilitation and research and who was not involved in the study for his views. To assess the transferability of the findings, methods employed in data collection, data analysis and interpretation were properly described. In addition, several of data analysis documents are available which gives others researchers the ability to transfer the findings of this study to other research projects. To address the dependability, the research design and its implementation, the operation details of data gathering and reflective appraisal of the thesis were reported in details (Shenton, 2004). The confirmability was achieved through the process audit trail which allows any observer/ non-researcher to trace the course of research step by step via the decision made and the procedures that lead to that decisions.

5.3 Results

Thematic analysis identified six (6) major themes and seventeen (17) sub-themes from multiple stakeholders. All themes and sub-themes identified fall under the contextual factors classified within the ICF. Individuals with a TSCI expressed their experiences in form of barriers and facilitators to reintegration. These were confirmed by other stakeholders in their views for what is needed for an optimal community reintegration. Table 5.3 outlines the themes and sub-themes that emerged during analysis. Verbatim quotes were used as an exemplary descriptions of participant responses to provide the evidence of the themes illustrated.

Table 5.3. Themes and Sub-themes identified by multiple stakeholders.

THEMES	SUB-THEMES
NATURAL ENVIRONMENT AND HUMAN- MADE CHANGES TO THE ENVIRONMENT	➢ Home environment ➢ outdoor environment ➢ Leisure and recreational facilities
PRODUCTS AND TECHNOLOGY	➢ Transport ➢ Assistive Technology
SUPPORT AND RELATIONSHIPS	➢ Support from family and friends ➢ Dissolving relationships ➢ Health professionals
ATTITUDES	➢ Unequal society ➢ Lack of Education and sensitization
SERVICES, SYSTEMS AND POLICIES	➢ Social support systems ➢ Lack of policies on employment after the injury ➢ Discrimination concerning employment ➢ Lack of alternative skill training after the injury
PERSONAL FACTORS	➢ Individual's self- efficacy ➢ Lack of confidence and sense of belonging ➢ Faith as source of motivation

Theme one: Natural environment and human- made changes to the environment

It became evident that the natural environment and human-made changes to the environment influenced reintegration of individuals with a TSCI into their communities. Several constraints related to the natural and human-made changes to the environment were highlighted by individuals with a TSCI. These were experienced at residential and societal/community levels.

- ***Home environment:***

In this particular study, the home environment was highlighted as one of the major barriers in the process of reintegration into normal life after sustaining a TSCI. The lack of adequate space in homes in order to manoeuvre the wheelchairs were cited as challenges that hampered individual's independency as illustrated in the quotes below.

> *"My house is too small, if I must get out of the bed, someone must take me from the bed straight to the wheelchair outside. My house is really small and I cannot move around with a wheel chair" (James).*

> *"When I got home from the rehabilitation centre everything was difficult. I was able to do almost everything by myself but it was difficult because I do not have enough space to move around the house with a wheelchair" (Tom).*

The lack of the space in their homes further impacted on individuals' ability to perform basic functions such as bathing and toileting. In these case, some participants shared how they adapted to their routines in order to function independently. These are illustrated in the following quotes.

> *"The other thing that is so difficult for me is to wash myself. I would love too and I do have a bath but the bathroom is too small, I cannot go there with a wheelchair. What I have now is what we call a bed bath (basin). It means sitting on the bed and then bath using a basin. It is very challenging for me" (Mary).*

> *"Once I am given a bed bath, I can do the rest like brushing my teeth, shaving and washing my face. But there is a big problem getting in the shower and wash myself because the shower is not designed for someone with disability like me" (John).*

"Another thing is that, I do not like to use this thing (Condom Catheter) I would like to use the toilet but I do not have the toilet for the disabled. Even the toilet I have is too small and I cannot go there with a wheel chair" so I use a bucket to ease myself" (James).

Although some of the participants shared how they could adapt to the new reality, others found it difficult and were forced to leave their homes in search of comfort. This is highlighted by the following quotes.

"After I got this accident, I was there by my house in Worcester but it was not good at all. I could not move around with a wheel chair. Always when I wanted to get out, someone must lift me and take me out. It was not good at all. It was not right, that is why I decided to come here (in nursing home)" (Peter).

"I feel much better here (nursing home) because I have enough space to move around with my wheelchair, in my house it was not possible, it was not easy because the house where I lived was to small" (Mark)

The challenges posed by the lack of space at home experienced by individuals with a TSCI were confirmed as obstacles to community reintegration by other stake holders too. Rehabilitation professionals highlighted the issues hampering independence as illustrated in the following quotes.

"*In order to facilitate full participation at home, the house must be wheelchair friendly, there must be enough space in the house for them to move around. The toilet must be accessible, the bathroom must be accessible, the kitchen must be accessible and they should be no stairs in the house for individuals with a TSCI to move independently" (RP1*).

"*As a professional and researcher myself, I am aware of challenges individual with spinal cord injury face when they get back home from rehabilitation centres. For example, the houses are not wheelchair friendly, the space in the house is too small, toilets and bathrooms are not accessible, kitchens are inaccessible so all these challenges need to be addressed by different stakeholders in order to facilitate home reintegration after spinal cord injury and home modification is important where necessary" (RP2).*

Other stakeholders such as caregivers and members of associations working for people with disabilities confirmed the issues of accessibility too.

"According to my experience, the personal assistant such as care givers or family members are very important to assist when necessary. However, the toilet and bathrooms should be made accessible, the kitchen should be modified, there should be no stairs in the house or if there are stairs, someone should be hired to build the ramps to facilitate the movement of the injured person around the house" (CG1).

"For me full reintegration after spinal cord injury means to allow persons with spinal cords injury to function independently, to function normally or near normal in all aspects of social life starting from home environment. This means that after spinal cord injury different things in the house such as toilets, bathrooms and kitchen must be modified to fit the needs of the injured person in order to allow full participation. In addition, there should be enough space in the house to manoeuvre the wheelchair" (MQASA1).

"*However, since I had money saved before the accident, it was most important for me that most of the things in the house including the toilet, bathroom, and bedroom's cupboards were adjusted to fit my needs. So home modification is very important in order to facilitate reintegration after the injury" (PRDPO1).*

- ***Outdoor environments***

In addition to the home environment, the outdoor environment proved to be challenging for individuals living with a TSCI. These included the natural environment, buildings, streets and pavements. Due to the challenges experienced outside of their homes, individuals with a TSCI are severely hampered in community activities as illustrated below.

"The side roads in my area are very bad, it is really not for people with wheelchairs. Even the strongest paraplegic like me struggle to move around with the wheelchair that is why most of the time I do not like to go out because I know that I will struggle" (James).

"When I get out of the house everything is gravel and it's difficult to move with a wheelchair. In my community all these things are so difficult to overcome. The environment is so difficult to Access. No ramps and no sidewalks for people with disabilities" (Mary).

The sentiments above were confirmed by others stakeholders who expressed the impact of environmental barriers to reintegration following the injury. They highlighted the need for outdoor environmental modification and improve of services to facilitated full integration of individuals with TSCIs into their respective communities.

"When it comes to physical environments a lot of need to be done for wheelchair users access. The natural environment is inaccessible, streets need to be modified, no pavements, also a lot of public buildings need to be modified to fit the needs of wheelchair users" (RP2).

"I know the City's vision is that we run full transport services for individuals with disabilities but there is still a gap to be closed between the journeys from home to the bus stations. There are a lot of things that need to be changed such as pavements, curves and walking paths for wheelchair users" (PRTSID1).

In addition, other stakeholders highlighted that public amenities were inaccessible for individuals living with spinal cord injuries.

> *"For example most of the public toilets seats are too low or the toilets are in the tinny space where by you cannot move with wheelchair. There are really many things that need to be changed like for example ATMs are either too high or in enclosed places that you cannot move with a wheelchair. Even if you go inside the banks, there are no help desks for people with disabilities" (RP3).*

> *"I think there should be a help desk in the bank for the wheelchair users, there should be modified ATMs for wheelchair users" (PRDPO2).*

> *"People talk about not having infrastructures that are wheel chair friendly you know! Like simple things like disabled public toilets you know! Things like isles in the supermarkets must be wide enough for wheelchair manoeuvre" (MQASA2).*

- ***Leisure and recreational facilities:***

Lack of entertainment and recreation facilities also proved to be a barrier to reintegrating back into the community as indicated in the quotes bellow.

> *"I like being active but there is no where I can go. I used to like playing basketball as well as soccer before the accident but now I am stuck in the wheelchair as there are not recreational facilities available. There should be adapted sport and recreation facilities for people with disabilities" (Paul).*

> *"Another thing is that no recreational facilities for individuals with disabilities. You know when you get injury you might not be able to use other able bodied facilities like gyms or other recreational facilities. I think Government should allocate enough resources to invest in creation of recreation facilities that cater for individuals with spinal cord injuries and disabilities at large" (Nick).*

Theme two: Products and technology:

- ***Transport***

Access to appropriate transport is vital for people with disabilities to get in and out of the communities. However, it is evident that negative attitudes of taxi drivers towards individuals with a TSCI was a key contributing factor to inaccessible transport services. It is clear that

some of the taxi drivers would take advantage of a wheelchair to charge an extra fee for transport. These are highlighted in the quotes below.

> *"Transport is a big problem you know! I cannot use public transport because this guys (taxi drivers) do not want to carry people in wheelchairs. So sometime if I want to go somewhere like the beach my brother must hire a private car to take me there which is very expensive. So sometime I end up not going anywhere because it is so expensive to hire the private transport" (Monica).*

> *"Those guys (Taxi drivers) do not want to take us because we are in the wheelchair. Even those who will be willing to take you will charge you a lot of money more than what a normal person would pay. Eish! It is so difficult to be a disabled person you know? How can you pay an extra for transport and you do not even have a job?" (Tom).*

Challenges related to transport extended beyond public transport. Someone who had his own car highlighted challenges related to parking. He mentioned issues such as the availability of designated parking for persons with disabilities or the use of these designated parking spaces by able bodied people.

> *"So transport for me from A to B is not a problem at all. The only problem is that, in many places you find that there are not parking designated for persons with disabilities. Even those that are available sometime you find that they have been taken by able bodied people" (John).*

Transport related issues impacted more than just moving around in the communities. It affected employment, learning activities and medical appointments as illustrated below.

> *"The other thing is transportation and I am struggling a lot. You see I stay in… (Mentioned the name of the township) and I have to come here to… (Mentioned the name of town where the participant is attending a learner ship) four days per week for this learner ship and I must pay someone to bring me here every day because I cannot use normal taxis as taxi drivers do not give a damn. Most of the time I miss school because I do not have transport. This is really giving me a lot of stress because I am using a lot of money for transport" (James).*

> *"Transport for disabled people is not available here and it is so difficult to use the normal public transport. For example, I was actually considering to go back to physio but I have got no transport to take me there you see! I was going to sign up for physio because I do have my back problems that I need to sort out but I am not sure how to get there as I have got no transport" (Tom).*

> *"I would like to get a job but the problem is transport to get to work. Actually I got a job at the day hospital but I could not take it because I cannot get there. I need a hired vehicle to take me there because it is uphill from where I stay and I cannot get there with a wheelchair" (Ana).*

Other stakeholders also offered their views on issues regarding transport. Their views were that transportation policy should be part of any national strategy. They emphasised that government and/or employers should make it a part of the package for individuals with disabilities these is highlighted bellow.

> *"Government must provide enough resources for individuals with disabilities such as transport services that are wheelchair users friendly as we know that it very difficult for wheelchair users to use normal public transport" (RP2).*

> *"I know that there is a company called dial a ride that provides special transport for people with disabilities but getting into that system is still a big challenge. In addition, this services are not operational in the whole South Africa only in few major cities. So their services must improve and government must provide enough resources to facilitate and improve this services and make them available for the whole of South Africa" (CG3).*

> *"When it comes to transport for individuals with disabilities, it is still a major problem. The only hope is that is to approach the potential employers and convince them to provide transport services for their employees with disabilities. Employers must make systems so that the transport must be part of the package when they employ individuals with disabilities" (PRDPO3).*

- **Assistive technology:**

In addition to removal of physical barriers related to infrastructures and transportation, stakeholders also highlighted how assistive technologies could play an important role to reintegration where physical environments are still major barriers.

> *"I think we need to think differently, we need to think about technology and how we use that, how we use platforms because we spoke about physical environment we do not have this, we do not have that, we do not have accessible buildings, but let's think about technology where people can do things online, let's have assistive technology so that they can do things on computers and do the things and teach themselves. So there are many options out there" (RP1)*

> *"Most of the work we do our days is mind based. Mind based I mean that with computers we can now do a lot even if you are physically disabled. The computers can allow you to do a lot of things even if you are physically disabled. You can teach yourself. It is a matter of those who wants to help and those of disabilities who want to be creative as well" (PRDPO4).*

> *"Computer skills have really opened up the world. So now with technology Quadriplegics can do a lot with computers now. I know 2 people who are quadriplegic and they are doing mouth painting and they are doing well and they are very happy" (CG4).*

Theme three: Support and Relationships:

Family members, friends, health care providers, neighbours and strangers may contribute to the environmental factors that influence individuals with spinal cord injuries both as barriers and facilitators.

- ***Support from direct families and close friends:***

Some individuals with spinal cord injury expressed how family members and friends have been there for them when needed.

> *"I was not always going to church but now I do go to church every Sunday. My mum and a friend of mine we are together in this you know? They always encourage me to go to church with them every Sunday" (Ana).*

> *"And because my hands are very weak to push the wheelchair, my brother always takes me out (he pushes me) I like to go out to get the sun for my health. And if I want to go to the clinic my brother always pushes me there. The clinic is a bit of a distance from here but my brother does not mind to push me there and if my brother is not available my sister in-law pushes me" (Monica).*

> *"I have a lot of friends currently, (the participant quote) you know there is a saying that when days are dark then friends are few. With me when days were dark friends were actually more. I have never been alone you know! I am always surrounded by people and they help me in anything that I need. I have actually got this lovely lady she is a special friend to me she helps me a lot. Any time I need anything like going to the hospital for medication or going out for entertainment she is always there for me" (John).*

Rehabilitation professionals and caregivers also highlighted how support from family members and close friends is important in helping individuals with spinal cord injury to get back to community life.

> *"I think family members and friends should always be there to give support to injured person when needed. However, they must also be given a kind of incentive just to encourage them. As you know, when you are taking care of a person with disability you intend to lose your own friends and your own leisure time" (CG5).*

> *"Support from family members and close friends is important and it can play a valuable role in facilitating individuals with SCIs to reintegrate back into communities" (RP2).*

- ***Dissolving relationships:***

Although family members and friends provided social support, this was not for all participants. In some case, family members saw people with a TSCI as a burden to such an extent that some individuals were even forced to leave their home in search of comfort and probably in order to save their relationships with their direct families. These is illustrated below.

> *"When I got home from the hospital I was staying with my mother and she was helping me but at later stage our relationship because so tense and then I decided to come and live here (Nursing home) and it was a good decision because it was not good for two of us. But now our relationship is back to normal" (Peter).*

> *"The relationship with my family is not good now. Immediately after the accident they were nice and helping here and there when I needed an assistance but now it is like they are tired of me. It seems as if I am a burden to them now" (Tom).*

> *"I do not have any support from my cousins and no one even bother to ask how I feel you see. I do not want to lie Mr. (calling the researcher's name) when they see me is hi hi as if they do not know me anymore" (James).*

It was also evident that in some cases friends become fewer as time passed by after the injury.

> *"I also had a lot of friends before the accident and when I got home from the rehabilitation centre they all came to welcome me but as the time went by they all disappeared from me" (Nick).*

> *"I used to have many friends but after the accident they all left me. Because I was working I used to organise parties and invite them over and we chill in my house or we go out but now that I am in the wheelchair and I cannot do much anymore they all run away from me" (Tom).*

- ***Influence of Health professionals***

Some individuals with spinal cord injuries mentioned how health professionals helped them to stay connected to the other people and the outside world in general. These are expressed in the following quotes.

"The rehab team was very good. The good thing is that they made me feel that I was not alone. I met many people that are like me some were even worse. And it made me feel good. For the mobility they actually prepared us straight forward that it's now time to change that you will have to adjust to the new life and it is not going to be the same like before" (John).

"Another thing is that in the rehab we also did a wheelchair racing for fundraising for other people with disabilities. So that was cool. We met other people with disabilities while doing something helpful for other people with disabilities" (James).

"In the rehab I learnt a lot like how to work on the computer, how to paint, in fact things that can help to create job for myself. They also helped us how to type words on our cell phone and computer using a stick in our month so now I can communicate with my friends when I want too. So now I do not feel isolated" (Mark).

Theme four: Attitude:

The attitudes and behaviours of family members, friends, neighbours and strangers contribute to the contextual factors that influence reintegration into communities following the injury.

- ***Lack of education and sensitization:***

Individuals with a TSCI felt the need for able bodied citizens to be educated and not to discriminate against them based on their abilities or disabilities. They indicated that able-bodied people should tolerate the differences and embrace the diversity of humanity. These are apparent in the following quotes.

"I think the public must be made aware about physically disabled people. I think it is important to educate people a lot and let them know that people with disabilities are not stupid or something like that. Much as they cannot walk like able bodied people but they are not stupid everything else is the same. Their brains work exactly the same like ours we have the same interest like they do" (Paul).

"Sometimes you hear people gossiping about you as if there is something wrong with you. There is nothing wrong about me we are the same. People must be made aware of disabled people. Some people do not know how to treat you when they see you in the wheelchair" (Tom).

"Their attitudes make me sick, I think because of their myths and beliefs some of them think that us people with disabilities we are curses. They need to be educated, they need to know that we are human beings like them" (Nick).

- ***Unequal society***:

It is evident that some of able- bodied people are ignorant on the reality of life of people living with disabilities and some may go as far as taking advantages of disabled individuals. These are reflected in the quotes bellow.

> **"***I am paying more than normal fee for public transport you see! I do not understand why. Maybe it's because I am disabled you see maybe because I am in the wheel chair. For example, if I go from my place to Cape Town it is only R25 but sometime taxi drivers ask you even to pay R 100. So why must I pay more than what an able bodied pay? That one is really frustrating me" (James).*

> *"People here used to see me as normal person and everyone used to have a good relationship with but after I got this accident people changed their attitude towards me. They do not care anymore they see me as a burden now" (Monica).*

Theme five: Services, Systems and Policies:

Lack of social support systems, lack of employment policies in certain companies after the injury as well as discrimination concerning employment possibilities and lack of training skills for an alternative employment after the injury may hamper the community involvement following the injury.

- ***Social support systems:***

Social support is a key element in the lives of individuals with a TSCI as they return home or their communities from rehabilitation centres. Social support was emphasized by stakeholders as an important part of community reintegration after the injury.

> *" The other thing is that there are no social support structures. Social support group should be available to help those ones that do not have anyone to take care of them after the injury. There should be someone during the week who can go to those with no caretakers to see if they can help them with something they need from the shop. Even if it means just talking to them at least 1 or 2 hours a day it can make a big difference" (CG6).*

"I think they should be social support in the community to help these individuals once they are discharged from the rehabilitation centres. Government should train community caregivers who will be taking over these people once they are discharged and sent back to their communities because we cannot do everything as rehab professionals" (RP3).

"I think people in the community must come together specifically peer support from people of spinal cord injuries themselves. I think this is a catalyst of breaking barriers to reintegration because people can meet and talk to each other, they can learn from each other and encourage each other. For example, if I see that Mr/Mrs X is well integrated and yet we have the same injury, it will encourage me" (PRSPO5).

- ***Lack of policies on employment after the injury***

This was expressed by both individuals with a TSCI and other stakeholders

"Before I got this accident, I was working with this company as a driver, after my rehabilitation I could not go back to work because I was in the wheelchair. I called them to find out if they could give an alternative job. They said that they will call me back but I never hard form them again" (John).

"I was doing all kind of manual work. After the accident I did not give up I tried different things like painting, all different kind things man to keep myself busy. I wish government can give me a job you see! The job that I can do with my disabilities" (peter).

"I know some people do not want to work after the injuries. But those that want to work must not be discriminated because of their disabilities. They should be given a chance like able bodied persons. We must have employment equity policy. People must not get tenders from any department if they do not have a plan to promote equity into their businesses. Ten percent of employment in any company should focus on disabilities" (RP1).

- ***Discrimination concerning employment possibilities***

Discrimination in term of employment based on race and physical disabilities were highlighted by both people with a TSCI and other stakeholders.

"I think government is discriminating us due to our race. Because I am a white person I cannot get a job. Most of the job adverts say "only black people must apply". I also need to get ahead in my life but I cannot even send my CV because most of job adverts clearly states that only blacks must apply" (Nick).

"The employers do not want to employ people with disabilities. Especially people with physical disabilities because they do not want to adjust the work environment in order to meet the needs of disabled people. So I think they should not be any discrimination towards employment opportunities based on any condition including people with disabilities" (RP3).

"People do not want to employ individuals with disabilities because of negative stigma attached to the person with disabilities. So he has to turn every one or two hours. For that he or she not going to be productive." (PRDPO1).

- ***Lack of alternative skills training services***

Stakeholders were of opinions that skills training programmes could be implemented that would assist young individuals who sustained a TSCI to venture into an alternative carrier path

"You see most people who got spinal cord injuries used to do physical (manual) work and they cannot go to the same employment after the injury. I think there should be programs like call centres programs or any other programs that can be able to train the individuals with disabilities in skills that can facilitate them to get like office jobs or something like that" (CG2).

"The only way to create the job opportunities for individuals with spinal cord injuries is to introduce them to some companies that are willing to mentor them and train them in different skills that can meet their conditions. For example, they can train them in phone operators, call centres or even computer skills" (PRDPO3).

Theme Six: Personal factors and believes:

The last theme that had influence to home and community reintegration was personal factors and believes. This theme was only related to the experiences as expressed by the individuals with a TSCI. This included individual's self-efficacy, lack of confidence and sense of belonging as well as faith as a source of motivation to reintegration.

- ***Self- Efficacy:***

As a facilitator to reintegration, some participants described statements about themselves that reflect their general self- efficacy and their personal believes that they have skills and the ability to overcome challenges.

"Life of disabled is too difficult. I am living this life of wheelchair you know. It is not easy but I am a man. I will not give up" (James).

"I would like to go further with my education so that I can get a better job. Like I said it is a challenge but a challenge you have to challenge it. So I can do it and I will go ahead and do it. I am a very positive person" (John).

"There are many places which are not comfortable but you can make it comfortable for you. You can make life easier even if it seems very difficult. If you choose to be negative, then everything will be difficult for you. I know there are many challenges. The environment is so difficult to access but with determination you can always get where you want to be" (Tim).

- ***Lack of confidence and sense of belonging:***

Some individuals with a TSCI did not feel confident enough to go back to the public areas including returning to their previous work environment after the injury. These are apparent in the quotes below.

I also used to do part time event planning and entertainment before the accident. But because my job requires me to speak in front of big clouds and be sociable, I noticed that after the accident I do not have the same ability and confidence to walk up to people and speak over the mike again" (Mary).

"Living with spinal cord injury is like an emotional scar. The social impact is like I feel like I am not fit in the society well. I cannot keep up anymore. I cannot do the same thing I used to do before the accident" (Monica).

Some of the participants did not have enough confidence to continue or initiate intimate relationships after the injury**.** Negative self-image and fear for rejection seemed to be a driving force to this lack of confidence as highlighted below.

"I am not married and I do not have a boyfriend. How can I get a boyfriend when I am in wheelchair like this? I am not even sure if I can have a satisfying sex you know! Sometimes I feel like I should try but I am scared" (Mary).

"At the moment I do not have a girlfriend. I used to have one before but she left me immediately after the accident. Now I do not have one and I am scared to approach any girl when I am still in this wheelchair. It is not good for me at the moment. What about if I approach someone and she rejects me because I am in the wheelchair? I am really scared my brother" (Tom).

"And right now I do not know if I should be in a relationship being in this condition. Think about trying to have sex and I did not try it ever since I had an accident. It has been 3 years now being in this condition and I am very nervous. Sometime I feel like I should wait until I get married but at the same time I do not want to get married in this condition. I feel nervous and shy" (Ana).

- ***Faith as source of motivation to reintegration:***

Some of the individuals with spinal cord injury highlighted faith in God as the way of moving forward and upwards.

"Some time you ask for help at home and people do not want to help you instead they get angry with you. But you know? I tell them that only God knows why he put me in this chair. God put me in this chair for a reason because he gave me a second chance so life must go on" (James).

"I really hate the attitude from some people around my community. They say that now you are disabled and you cannot do anything for yourself. And I say to them it's alright God is on my side, he gives me strength and I know I can do anything with him on my side" (Tom).

"You have to have a good relationship with God. If you have good relationship with God everything is possible. I know that there are many things against me, I know that there are many barriers, many battle to fight but I know with God all is possible. As long as I do it the way he wants me to do I can overcome anything" (Tim).

5.4 Discussion

Many individuals who has sustained a TSCI often require long term assistance with transition back to their communities from rehabilitation centres (Muller et al., 2012). Although the ultimate outcome of rehabilitation for persons with a TSCI is to fulfil their social role and optimize community reintegration, many are restricted in this aspect due to personal and environmental factors. This is a dynamic interaction between a health condition, body function and structures, activities, participation and contextual factors as illustrated by the ICF (Hawkins et al., 2015). To gain a deeper understanding of reintegration into communities after sustaining a TSCI, the experiences and views of multiple stakeholders such and individuals with a TSCI,

caregivers, rehabilitation professionals, representatives of organizations for PWD were explored in this study.

As stated earlier in this chapter, the contextual factors of the ICF refer to the physical, social and attitudinal environment in which people live and conduct their lives (WHO, 2001). As the contextual factors include both environmental and personal factors, researchers pointed out that living space and factors related to home are some of the main issues with the environment (Heywood, 2004; Steins, 2003 & Hurst et al., 2002). On closer investigation, individuals with a TSCI may experience difficulties with access to their homes after discharge from rehabilitation centres. These barriers or factors associated with accessibility corresponds with the ICF domain "*Natural environment and human-made changes to the environment"*.

The barriers related to inaccessibility and lack of adequate space experienced by participants in this study was a challenge to reintegration "*My house is too small, if I must get out of the bed, someone must take me from the bed straight to the wheelchair outside. My house is really small and I cannot move around with a wheel chair" (James).* These challenges are consistent with other studies (Carr et al., 2017; Nunnerley, 2013 & Boschen et al., 2003) identified that lack of adequate space in one's home were one of the barriers to residential reintegration following a SCI. According to Ahmed et al. (2018), independent living or reduced dependency on others in one's residence was difficult as most of the individuals with SCI did not have access to disability friendly residences. Dijkers (1998) stated that community living describes the situation of an individual who fully participates in all aspects of social life of his or her family, community and society and he recommended that residential setting should be considered very important as participation at this level is the first step towards successful social and community reintegration.

Contrary to the others studies, this study highlighted the unique challenges faced by individuals with a TSCI due to socio-economic inequalities in South Africa. Although the right to access adequate housing for everyone is granted in the constitution of the Republic of South Africa (Parliament of the Republic of South Africa, 1996), the majority of people with disabilities including those livings with a TSCI still have little hope of accessing adequate and independent housing (Integrated National Disability Strategy, White Paper, 2009). The existing dwellings/ shacks are often inaccessible due to poor design, location and lack of enough space and or overcrowding. *"I feel much better here (nursing home) because I have enough space to move around with my wheelchair, in my house it was not possible, it was not easy because the house where I lived was to small" (Mark)*. As a direct result of this, individuals with a TSCI are forced into institutions and nursing homes against their will. *"After I got this accident, I was there by my house in Worcester but it was not good at all. I could not move around with a wheel chair. Always when I wanted to get out, someone must lift me and take me out. It was not good at all. It was not right, that is why I decided to come here (in nursing home)" (Peter).* This is in contradiction to the Article 19 of the Convention on the Right of Persons with Disabilities (CRPD) (Assembly United Nations General (2006) that emphasizes the importance of granting individuals with disabilities the opportunities to choose their place of residence and where and with whom they live on an equal basis with others and that they are not obliged to live in a particular living arrangements. According to this article, individuals with disabilities should have access to a range of in-home residential and other community support services, including personal assistance necessary to support living and inclusion in the homes and communities. The challenges however, remain on how to achieve this. Parker and Fisher (2010), suggest that an integrated and coordinated public and private sectors should combine regulations and funding, market for accessible homes, incentives, interagency coordination, information and protection from discrimination in order to increase the number of accessible homes.

Barriers to reintegration in this study was also experienced as far as the environment outside their homes. Inaccessible public buildings, gravel roads, lack of ramps and sidewalks were the major barriers to the community life involvement. *"When I get out of the house everything is gravel and it's difficult to move with a wheelchair. In my community all these things are so difficult to overcome. The environment is so difficult to Access. No ramps and no sidewalks for people with disabilities" (Mary).* These findings are also in agreement of previous studies that reported natural and built in environment as barriers to community reintegration (Barclay et al., 2016; Hawkins, 2015; Pershouse et al., 2012; Price, Stephenson, Krantz, & Ward, 2011; Kuipers et al., 2011; Carpenter, Forwell, Jongbloed, & Backman, 2007; Whiteneck et al., 2004; Boschen et al., 2003). In order to overcome the above mentioned barriers to reintegration, South African government with other stakeholders such as private institutions and NPOs should work together to increase the number of accessible housing and encourage associations of people with disabilities, local authorities and housing cooperatives to work with developers to design or provide disability friendly housing with enough space, accessible bathrooms, kitchens, living rooms for individuals with a TSCI to improve their self-care and facilitate their residential and community living life at large. In addition to accessible housing, modification of existing outdoor environment, and creation of new disability friendly environment is of paramount to facilitate community engagement for individuals with disabilities.

On closure look at the "*product and technology*" as well as "*services, systems and policies* domains of the ICF, it was apparent that being able to access appropriate transport is very important for individuals with limited mobility such as those of a TSCI to get to work or other social and recreational activities. However, problems with transport were consistently cited by the individuals with a TSCI in the present study as a major obstacle to their ability to fully participate and reintegrate in community life. *"Transport is a big problem you know! I cannot*

use public transport because this guys (taxi drivers) do not want to carry people in wheelchairs (Monica). These findings are once more consistent with previous reports in literature. Numerous studies (Kennedy et al., 2010; Lysack et al., 2007; Schopp et al., 2007; Carpenter et al., 2007; Whiteneck et al., 2004, Boschen et al., 2003) have previously identified lack of transport as a major barrier to community life engagement following SCI.

Although access to a modified car facilitated getting out to the community in this study, this did not necessarily mean the access to the community as in some cases unavailability of the disabled parking spaces posed a problem to community engagement. Furthermore, those parking that could be available would be sometimes taken by able bodied individuals. This confirms previous findings in literature. The study conducted by Carpenter et al., (2007) reported that an appropriate public transport and ability of individuals to drive own car and having access to disabled parking spaces and fully service petrol stations were an important facilitators to community integration following SCI.

Further to the ICF domain "*services, systems and policies*" in this study, it was also very clear that lack of policies on employment, employers' discrimination concerning employment possibilities played a negative role on employment after the injury. *"The employers do not want to employ people with disabilities. Especially people with physical disabilities because they do not want to adjust the work environment in order to meet the needs of disabled people. So I think they should not be any discrimination towards employment opportunities based on any condition including people with disabilities" (RP3).* This was further complicated by lack of transport as some participants highlighted that there was no need for them to seek for employment when they did not have access to transport to go to work. *"I would like to get a job but the problem is transport to get to work. Actually I got a job at the day hospital but I*

could not take it because I cannot get there. I need a hired vehicle to take me there because it is uphill from where I stay and I cannot get there with a wheelchair" (Ana). These findings are in agreement with what have been reported in literature. The studies by Lidal., (2007) and Conroy & McKenna (1999) also found that the most common barriers to employment was problems with transportation, discrimination of employers, health and physical limitations, lack of work experience, education or training, as well as physical or architectural barriers. According to Anderson et al., 2007 employer's role was positively associated with return to work following SCI. In order to overcome the above mentioned challenges, rehabilitation process need to focus on helping individuals with a TSCI to explore meaningful employment opportunities for better community reintegration. Other stakeholders including government departments should as well work together on interventions that should help individuals with disabilities to integrate back to the communities and help them to (re)enter job market, target to change discriminatory attitudes of employers or co-workers at the work place as well as they should arrange disability friendly transportation facilities and accommodation for individuals with disabilities.

The attitudes and behaviours of family members, friends, health- care provides, neighbours and strangers can contribute to the environmental factors that influence the lives of people with SCI, both as barriers and facilitators (Chan et al.; 2009). Attitudes at home may refer to family member's attitude, or it could refer to personal care assistance attitude (Boschen et al.; 2003). In this particular study, the ICF domains "*support, relationships* and "*attitudes* "were closely linked together. Most of the participants revealed that direct family members and friends helped them to reintegrate into their communities. *"And because my hands are very weak to push the wheelchair, my brother always takes me out (he pushes me) I like to go out to get the sun for my health. And if I want to go to the clinic my brother always pushes me there. The clinic is a bit of a distance from here but my brother does not mind to push me there and if my brother is*

not available my sister in-law pushes me" (Monica). This is closely linked to strong support from family members, friends that were identified as facilitators to reintegration into the communities after the injury consistent with previous studies that identified supportive relationships with one or two key people as an important facilitator to community integration (Barclay et al., 2016; Ripat & Woodgate, 2012; Hammell, 2004; Boschen et al., 2003). The study conducted by Hammell, (2004) concluded that close friends and family members should be involved in the rehabilitation process particularly during the transition to home where by key support people need to be actively engaged in the facilitation of social and community activities as soon as possible. Assistance and support provided by able- bodied people, as well as support from other people with disabilities represent an imperative help to people with disabilities.

Although support from direct family members and friends were identified by many as a facilitator to reintegration, a lack of support was also experienced as a barrier. In this case, the relationship with family members could be closely linked to *attitudes.* Negative attitudes of family members were highlighted in this study. *"I do not have any support from my cousins and no one even bother to ask how I feel you see. I do not want to lie Mr. (calling the researcher's name) when they see me is hi hi as if they do not know me anymore" (James).* Participants also shared how they were perceived by some of their family members as burden. *"The relationship with my family is not good now. Immediately after the accident they were nice and helping here and there when I needed an assistance but now it is like they are tired of me. It seems as if I am a burden to them now" (Tom).* Lack of family support identified in this particular study is consistent with previous findings in literature. A Canadian survey reported that while about two thirds of people with SCI in the excellent health identified the attitudes of their family and friends as facilitators to their social participation, 25% of those in poor health cited attitudes of family and friends as an obstacle to their social participation (Noreau et al.,

2002). In the study conducted in USA, Lysack et al. (2007) cited the attitudes at home as the top five barriers to community reintegration following a TSCI.

Health professionals can impact on community reintegration by enabling the individuals with SCI to have control in the rehabilitation process and choice with goals and direction via client-centred approach. Dwyer and Mulligan (2015) identified that an expectation of health professionals working with spinal cord injured individuals was that their patients would be constantly positive and engage in their rehabilitation and not allowing space for natural feelings of sadness or grief over their injury. This is supported by the present study. Health professionals particularly rehabilitation team were identified as facilitators that helped individuals with a TSCI to stay connected to other people and the outside world in general. Participants in this study mentioned that rehabilitation team made them feel good about their disabilities and prepared them physically to become independent in their respective communities. *"The rehab team was very good. The good thing is that they made me feel that I was not alone. I met many people that are like me some were even worse. And it made me feel good.*

Despite the fact the ICF has not fully classified personal factors, this domain is part of contextual factors and it can also play a big role as a facilitator or barrier to reintegration following the injury. Although it has been reported that individuals with SCI lack confidence in their abilities and have lower self-efficacy than the non-disabled population (Middleton et al., 2007), this is different in this particular study. The participants described statements about themselves that reflect their general self- efficacy and their personal believes that they have skills and ability to overcome challenges. *"I would like to go further with my education so that I can get a better job. Like I said it is a challenge but a challenge you have to challenge it. So*

I can do it and I will go ahead and do it. I am a very positive person" (John). Similar to Benight & Bandura (2004), higher self-efficacy was related to the perception of being able to overcome challenges and lower emotional distress. This is a reflexion of how positive self-efficacy might have played a positive role during reintegration. In addition to positive self-efficacy, some of the participants highlighted faith in God as a way moving forward and upwards. *"You must have a good relationship with God. If you have good relationship with God everything is possible. I know that there are many things against me, I know that there are many barriers, many battle to fight but I know with God all is possible. As long as I do it the way he wants me to do I can overcome anything" (Tim).* This is also in line with a previous report in literature. A study (Babamohamadi & Negarandeh, 2011) that aimed to identify coping strategies used by people with SCI living in community in Iran found that seeking help from religious beliefs e.g. Understating the disease as a divine fate and as a spiritual combat was one of the major theme that was identified by the participants.

Although positive self-efficacy and having faith in God were associated with reintegration in this study, for some of other participant's reintegration was challenged with luck of confidence and sense of belonging in the community as some did not feel confident enough to go back to the public including returning to their previous work environment after the injury. *I also used to do part time event planning and entertainment before the accident. But because my job requires me to speak in front of big clouds and be sociable, I noticed that after the accident I do not have the same ability and confidence to walk up to people and speak over the mike again" (Mary).* This is consistent with the report by Middleton et al., (2007) who argued that individuals with SCI lack confidence in their abilities and have lower self-efficacy than the non-disabled population.

5.5 Conclusion

The qualitative phase of this study added to the findings of quantitative results by obtaining a deeper understanding of the factors that influence community reintegration following a TSCI. These results are in line with the conceptual homework (ICF) that informs this study. Multiple stakeholders provided in-depth descriptions of how integration into communities following the injury is strongly influenced by various domains that falls within contextual factors of the ICF model.

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Chapter Six

Scoping literature review

Life is a journey that must be travelled no matter how bad the roads and accommodations.

Oliver Goldsmith, 1728-1774; Irish writer, poet and physician

Eugene Nizeyimana, Julie Phillips

Abstract

Background: Community reintegration programmes following a TSCI are needed in order to facilitate independent living, social involvement and engagement in productive activities.

Objective: The objective of this phase of the study was to review the programmes addressing community reintegration programme of individuals with a SCI.

Methods: A scooping literature review was used to achieve the objective of this phase of the study. A literature search was done in the different electronic databases including: Science direct, EBSCO (including academic search complete), CINAH, ERIC, Health Sources: Nursing/ academic edition, Master file Premier, MEDLINE, SocINDEX, Psych ARTICLES as well as manual search.

Results: The electronic search identified 269 and additional 3 articles from a manual search making it a total of 272 articles. After title/ abstract screaming, 262 articles did not meet the inclusion criteria and they were excluded. Thus only 10 articles were included for the review. The programmes identified were related to vocational rehabilitation programmes that were found to be beneficial in helping individuals with a SCI to gain employment following the injury. Other programmes such as: adaptive sports, outdoor recreational, health promotion and capacity building as well as technology aided programmes were also identified and played an important role in promoting community independence living skills, promote positive Self-efficacy by increasing confidence in abilities to set and achieve goals.

Conclusion: The results of this phase of the study highlighted the importance of vocational rehabilitation, leisure, sports and recreation programmes for successful community reintegration of individuals with a SCI.

6.1 Introduction and rationale

Traumatic spinal cord injury is a catastrophic event that is sudden and unexpected often affecting young individuals around the world (Ackery et al., 2005). Individuals affected by a TSCI have difficulties in performing activities of daily living which reduces their participation in social, recreational and economic activities. Rehabilitation of persons with a TSCI is therefore, an essential to return them to their previous level of function or as close as to it as possible. Community reintegration is an important component of the entire rehabilitation process especially after a TSCI since this is most likely to occur in young working individuals who have active family and social life (Sekaran et al., 2010). Community reintegration requires new learning, problem solving, adaptation to lifestyle changes and effective copping skills. Successful community reintegration following SCI is considered an important goal of rehabilitation process as this have been positively associated with self-esteem/ self-efficacy, quality of life and life satisfaction (Kennedy et al., 2012, 2012; Tonack et al., 2008; Middleton, 2007; Tate et al., 2002). A definition of community reintegration pertinent to spinal cord injury individuals refers to "resuming age/gender and culturally appropriate roles/statuses/activities, including independence/interdependence in decision making, and productive behaviours performed as part of multivaried relationships with family, friends and others in natural community setting" (Dijkers, 1998). This means returning to family and community life, engagement in normal roles and responsibilities, active contribution to social groups and society as a whole. With reference to the above mentioned definition, it is evident that there should be three major areas in community reintegration process namely: Independent living, social involvement and engagement in productive activities. Therefore, community reintegration programmes following disabilities are needed in order to facilitate this process. But what do we know about the existing programmes addressing community reintegration following a TSCI.

6.2 Aim of the scoping review

The main aim of this scoping review is to identify programmes designed to facilitate community reintegration for individuals who sustained a TSCI.

6.3 Methodology

A scoping method was used to meet the aim of this phase of the study. According to Arksey & O'Malley, (2005), Scoping review aim to map the key concepts underpinning a research area and the main sources and types of evidence available and they are commonly taken to examine the extent, range, and nature of research activity in the topic area. This method provides a descriptive overview of reviewed material without critically appraising individual studies or synthesizing evidence from different studies. Thus, the rationale of using scoping review in this study is that the main aim was not to critically appraise individual studies nor did it aim to synthesize the evidence from different studies but rather to identify programmes that address community reintegration following a SCI. Therefore, a scoping review was appropriate to achieve the main aim of this phase. In the present study, the scoping review was conducted in relation to the community reintegration following a TSCI as the topic area in order to map an existing literature on the programmes addressing community reintegration of individuals with a TSCI. The scoping review was based on the framework described in the literature by Arksey & O'Malley, (2005) and ensuring the recommendations made by Pham et al (2014). This framework comprises of the following five key phases: (1) Identifying the research question, (2) Identifying relevant studies, (3) Study selection, (4) Charting the data and (5) Collating, summarising and reporting the results.

6.3.1 Data sources/ Search strategy

The initial search was initiated in October, 2015 in the multiple databases including Science Direct, EBCOHOST (CINAHL, MEDLINE, ERIC, Global health, Health Source: Nursing/Academic Edition, MasterFILE Premier and SoclINDEX). The above mentioned data bases were selected to be comprehensive and to cover a broad range of sources of information on SCI and community reintegration. Reference lists of few randomly selected studies were also searched. Hand-searching of the key journals was also done to identify articles that might have been missed in database and reference lists. The limit date was set on the data base search to the articles that were published from January 2000 to December 2016. Significant studies were identified using any of the following keywords: Spinal cord injury, traumatic spinal cord injury, rehabilitation, community integration, reintegration, intervention, social participation, leisure activity, sports, recreation, vocational, employment, social support, programs.

6.3.2 Inclusion Criteria

Studies published in English between January, 2000 to December, 2016 were included if they addressed any community reintegration programme for adults (≥18years) who sustained a spinal cord injury.

6.4 Results

The overview of the types of the articles selected is provided in table 6.1 highlighting the author(s), year of the study, study design, aim of the study, study location, interventions types, main results and the research implications. The electronic search identified 269 studies from the selected databases: Science direct = 40, EBSCO (including academic search complete= 51, CINAHL= 50, ERIC= 8, Health Sources: Nursing/ academic edition = 45, Master file Premier= 8, MEDLINE = 48, SocINDEX = 14, Phyc ARTICLES = 5 and additional 3 articles from a manual search making it a total of 272 articles. After title/ abstract screaming, 252 were excluded as they were not related to programs addressing the community reintegration after SCI. The abstracts of 20 citations were then obtained and retrieved. Out of these 20 abstracts, 5 were excluded because they were duplicates, 2 were excluded because they only included individuals with brain injuries, 2 were excluded because they included individuals less than 18 years. Thus, 10 full text articles were included in the review. Figure 6.1 presents the flow chart of included studies.

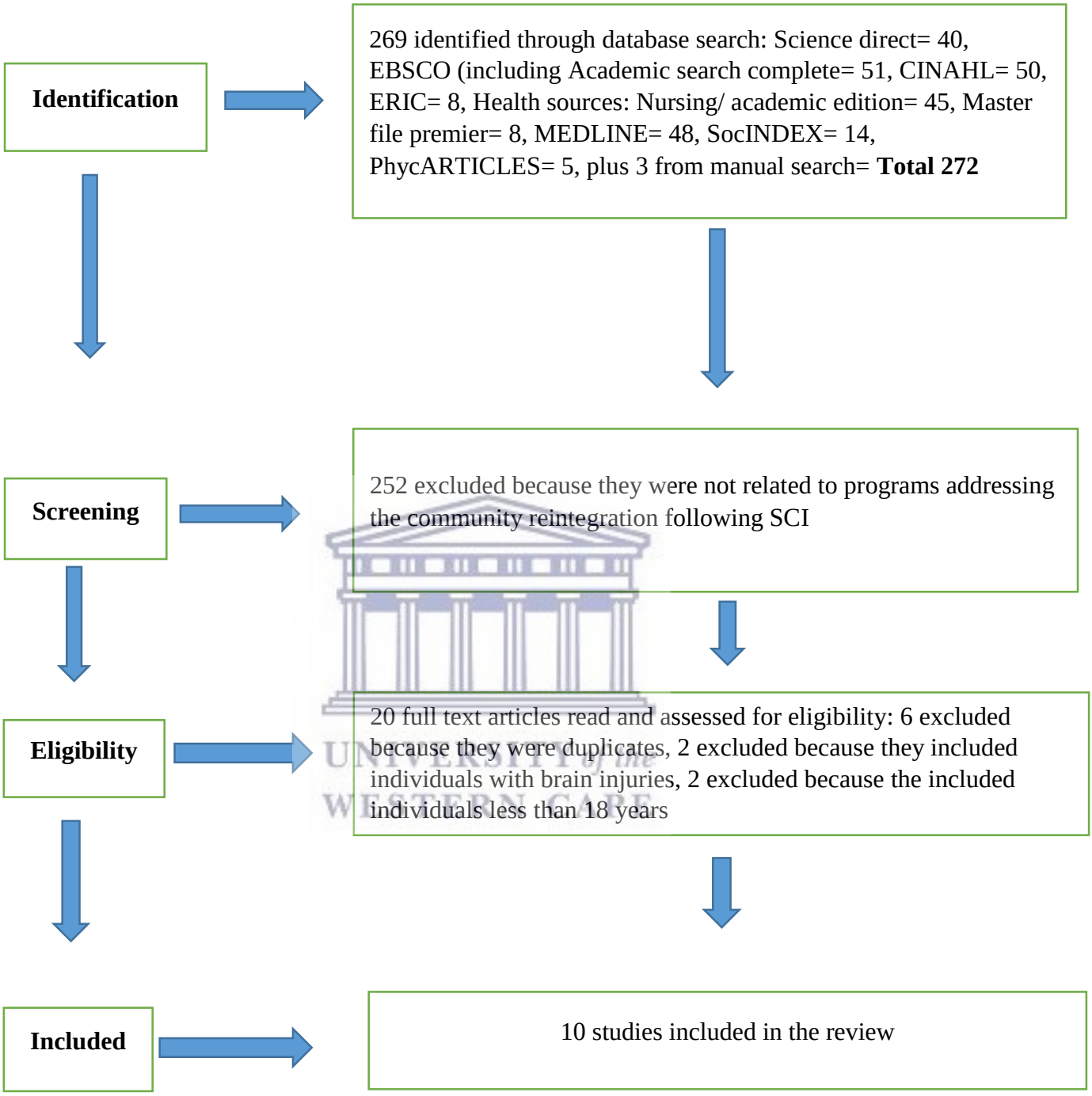

Figure 6.1 Flow Chart of included studies

Table 6.1 studies addressing community reintegration programmes based on framework described by Arksey & O'Malley, (2005)

AUTHORS & YEAR	STUDY DESIGN	AIM OF THE STUDY	STUDY LOCATION	INTERVENTIONS	MAIN RESULTS AND RESEARCH IMPLICATIONS
Lancioni et al 2015	A cross-sectional survey	To investigate the effectiveness of technology-aided leisure and communication programs to persons with SCI and post-coma multiple disabilities	Italy	The programs focused on enabling the participants to activate songs, videos, requests, text messages and telephone calls. These options were presented on the computer screen and activated through a small pressure micro switch by the man with SCI and a special touch screen by the post-coma man. To help the latter participant who had no verbal skills, with requests and telephone calls, series of words and phrases were made available that he could activate in those situations.	Both participants were successful in managing the programs arranged for them. The man with SCI activated mean frequencies of above five options per 10-minute session. The post-coma man activated mean frequencies of about 12 options per 20-minute session. The results of this study showed that the technology-aided programs for promoting leisure and communication opportunities might be successfully tailored to persons with SCI and person with post-coma multiple disabilities.
Sutton et al 2015	A cross-sectional survey	To investigate the impact of social support at home on health related quality of life (HRQOL) for individuals with SCI participating in the program of supported employment	USA	214 individuals SCI enrolled in Evidence- Based practice-supported employment (EBP-SE) program were followed up to determine the effectiveness of the program. Structured interviews were conducted prior to the enrolment into the program together baseline information of the participants. Data gathered prior to the program comprised of elements addressing employment, medical function and psychological data. The second interviews were conducted at the conclusion of the program (24 months following the baseline interviews). Data gathered at this stage comprised of competitive employment, quality of life and health care utilization	Study participants experienced an increase in HRQOL overtime. The initial level and rate of increase in HRQOL varied by groups based on their support status. Participant reporting no support at home experienced lower initial HRQOL but reached the same level of those who reported having support at home by the ninth month of follow-up. Quality adjusted life- years as measured by the area under the curve were approximately the same for both groups after 2 years. Participants in this supported employment program experienced the improvement in HRQOL beyond 12 months and extending to 2 years. Follow-up time for evaluation should extend beyond 12 months to assess complete improvements in HRQOL.

Ottomanelli et al 2012	Prospective, randomized controlled, multisite trial.	To examine whether supported employment (SE) program is more effective than treatment as usual (TAU) in returning veterans to competitive employment after SCI with 1 year follow-up.	USA	The subjects were randomly assigned to SE. The intervention consisted of supported employment vocational rehabilitation program called the spinal cord injury vocational integration program, which adhered as closely as possible to principles of SE as developed and described in the individual placement and support model of SE for persons with mental illness. The primary study outcome measurement was a competitive employment in the community.	Subjects in the SE program were 2.5 times more likely than the TUA-IS group and 11.4 times more likely than TUA-OS group to obtain competitive employment. SE, as well-prescribed method of integrated vocational care was superior to usual practices in improving employment outcomes for veterans with SCI.
Ottomanelli et al 2014	Prospective, randomized controlled, multisite trial.	To examine if supported employment program (SEP) remains more effective than treatment as usual (TAU) in returning veterans to competitive employment after SCI at 2-years follow-up.	USA	Subjects (n=201) were enrolled and completed baseline interviews: at interventional sites, subjects were randomized to SE (n=81) or TUA (n=76). At observational sites, 44 subjects were enrolled in a nonrandomised TUA condition. The intervention consisted of supported employment vocational rehabilitation program called the spinal cord injury vocational integration program, which adhered as closely as possible to principles of SE as developed and described in the individual placement and support model of SE for persons with mental illness. The primary study outcome measurement was a competitive employment in the community within 2 years.	SE subjects were significantly more likely to achieve employment (30.8%; 95% confidence interval [CI], 21.8e41.6) than either the TAU subjects at the intervention sites (10.5%; 95% CI, 5.2e19.7; P< .001). Or the TAU subjects at the observational sites (2.3%; 95% CI; 0.0e12.9; P<.002). Most subjects who obtained competitive employment did so in year1, and the average time to first employment was about 17 weeks.
Nuri et al 2012	A cross-sectional Survey	To evaluate the effectiveness of vocational training programme in enabling 261 individuals with disabilities to find	Bangladesh	261 individuals with disabilities were involved in different vocational training programmes and job placements. 67 individuals attended computer training programme for a duration of 3 months, 50 individuals attended electronic training programme for a duration of 4 months, 5 individuals attended garments operator training programme for a duration of 3 months, 45 individuals attended shop management training	60% of the individuals with disabilities that participated in the programme secured employment after the training. Of these, 74% reported that they were able to provide a better livelihood for their families, 92% reported increased social acceptance, and 83% reported improvement in the overall quality of life.

		employment in Bangladesh		programme for a duration of 1 month, 90 individuals attended sewing- machine operator training programme for a duration of 2 months.	The results of this study suggest that vocational training programme improved the r (e) entry of persons with disabilities into employment which in turn aided their rehabilitation.
Shem et al 2011	A prospective study	To improve the percentage of youth and young adults with SCI who access post-secondary education or employment opportunities and to improve quality of life.	USA	29 individuals with SCI enrolled in the program. The mentoring relationship was planned for 2 years. Program staff consisted of two physicians, program coordinator, program assistant, vocational counsellor and rehabilitation psychologist. The mentoring program coordinator monitored the progress of the relationships on semi-monthly basis and served as liaison to a vocational rehabilitation counsellor. Each mentee with SCI was matched with community-based mentor with or without disability, although an effort was made to recruit mentors with SCI. The over-arching goal of the mentoring program was to improve the ability of individuals with disabilities to access and maximally utilize the services available in the community. Mentor/mentee relationship were required to have a minimum of 3 contacts per month through in-person, telephone or electronic emails. The minimum number of assessment were four: at the time of the enrolment to the program, three months after the entry to the program (and every three months there-after until attempted entry to post-secondary education or employment and four months after entry to post-secondary education or employment.	Of 29 participants that were matched with mentors, 10 participants (43%) completed the program, with seven (24%) returning to school, two (6.9%) returning to work and one individual (3.4%) attending school part time. Although multiple barriers to success occurred, this program demonstrated that it could assist the youth and young adults with SCI to obtain post-secondary education and employment. This type of support system should be encouraged in order to improve the quality and satisfaction of life for young adults with disabilities.
Lundberg et al 2011	A cross-sectional survey	To examine changes in quality of life, mood stress and sports related competence for veterans of acquired disability who participated	USA	Veterans in this study participated in three separate group program. The first group consisted of five veterans with acquired disabilities such as TBI, SCI, Amputation and PTSD who participated in various adaptive sports and recreation activities including water skiing, kayaking, river rafting, canoeing, and fly-fishing, over a five-day period. The second group included six veterans with acquired disabilities who participated in a five-day fly-fishing camp. The third	The results identified significant pre and post-test differences in psychological health, overall quality of life, mood states including tension, depression, anger and sports related competence. The results of this study highlight the impact that therapeutic adaptive sports and recreation programs potentially have for combat veterans in areas of quality of life, reduction of mood disturbances and sports related competence.

		in therapeutic adaptive sports and recreational program		group included seven veterans with acquired disabilities who participated for five days in ski/snowboarding, ice skating, and Nordic skiing.	
Corway, 2011	A cross-Sectional Survey	To explore the Experiences and Perceptions of Spinal Cord Injured People who attended Outdoor Recreation Programmes	New Zealand	Individuals with SCI attended outdoor recreational programme (ORP) that included snow skiing, rafting, kayaking, climbing, bush walking and abseiling. At the beginning of the programme, each participant was given a booklet to record their goals and reflections of each day. Each day consisted of participating in one or more outdoor recreational activities. At the end of each day all participants met to discuss their highs and lows for that day and to prepare for the following day. Two (2) semi-structured interviews were conducted during the programme. The first interview took place at the beginning of the programme. This aimed to understand the reasons for attending the programme, what the participations thought that they would get out of the programme, their level of community participation prior to attending the programme, barriers to participation and general health. The second interview took place at 3 months follow up with an aim to understand the participants' experiences of the programme, their positive and negative perception of the programme, what changed in their lives during the course of the programme, barriers that they faced during the programme, what goals that they had set for the future and how those goals were related to the programme. How important they viewed the programme for themselves/ others and why.	The overall substantive theory that emerged from this study was how attendance at the ORP contributed to the participants with SCI reclaiming and living their lives. Participants indicated that they had benefited physically and psychologically from attendance, with the combination of these gains enabling them to engage more actively in social, recreational and vocational pursuits. This resulted in each individual beginning to reclaim or succeeding in reclaiming and living their lives successfully in the community. The participants felt that they now had opportunities and options in their lives. The results of this study will enable funders and providers of rehabilitation services to consider ORP as a beneficial adjunct to the rehabilitation and reintegration of individuals with SCI, especially for those individuals who have struggled to come to terms with their injury and have not successfully reintegrated back into their communities.

Block et al 2010	A quasi-experimental design	To evaluate changes in participant's self-efficacy ability to set/achieve goals and perceived independent living status following health promotion and capacity building program for individuals with SCI	USA	The program included ten full day sessions, twice a month at various locations around the states, between August and December of 2002 (First intervention group) and August to December of 2003 (second intervention group). Each day of the program was divided into morning and afternoon sessions. The afternoons were comprised of organized physical or recreational group activities such as in door and outdoor recreational activities. Indoor activities included strength training, aerobic conditioning and indoor wheel-chair sports. Outdoor recreational activities were sailing, sea kayaking, stunt kite flying, fishing, hand cycling, and sled hockey. The intervention took place in the community based settings including state parks, public libraries, and 2 university campuses using local activities and resources with the intension that participants would continue to access these after the project's conclusion.	Participants that attended the program gained independent living skills and confidence in their abilities to set and achieve a variety of goals in the area of education, employment, housing, transportation, accessing community resources and activities, participation in sports and leisure as well as health promotion. This is study indicate that health promotion and capacity building program increased independence, community access, and participation after SCI. Changes were observed in areas of intrapersonal, interpersonal, and behavioural functioning that indicated greater personal empowerment.
Hess et al 2007	A cross-sectional survey	To explore the experience of four individuals with paraplegia enrolled in an outpatient interdisciplinary sexuality program	USA	Four consecutive males with SCI were referred to the outpatient spinal cord injury sexuality program at an urban veteran's medical centre seen by an interdisciplinary team comprised of a nurse, physician, and psychologist. The nursing assessment included a focused clinical and sexual history and learning needs assessment. The patients were educated regarding safe sexual practice, adaptive equipment options, and provided with a mental health inventory which the completed independently or with unbiased help when level of the injury interfered with hand function. The patients were instructed to contact the clinic with questions, concerns and comments about effectiveness of treatment.	On completion of the program, participants felt that their questions had been answered and their emotional well- being had been appropriately addressed in a respectful environment and effective process. The results of this program suggest that availability of continued access to counselling regarding sexuality related issues is very important and that patients can benefit from an interdisciplinary approach in addressing functional and emotional needs.

6.5 Discussion

The programmes identified in this phase of the study were mostly related to vocational rehabilitation programmes, adaptive sports, outdoor recreational, health promotion, capacity building and technology aided programmes.

Supported employment and general vocational training programs

Four studies (Sutton et al., 2015; Ottomanelli et al., 2014; Ottomanelli et al., 2012; Neri et al., 2012) aimed to investigate the effectiveness of supported employment and general vocational training programs in relation to finding employment and improvement in quality of life of individuals with a SCI. According to the study by Sutton et al., (2015) individuals with a SCI who participated in supported employment programs had improvement in health related quality of life. The studies by Ottomanelli, et al., (2012) and Ottomanelli et al., (2014), reported that individuals who participated in supported employment programs were more likely to gain a competitive employment compared to those that had a standard vocational care while the study by Nuri et al., (2012) indicated that 60% of individuals with SCI who attended vocational training programme were able to find employment after the programme. The implication of the above reports to reintegration is that vocational reintegration programs are essential in helping individuals with a SCI to gain employment following the injury. However, supported employment programmes are more likely to help individuals with a SCI to gain competitive employment compared to usual vocational rehabilitation programmes.

Further to supported employment programs, one study (Shem et al., 2011), reported on mentoring programs that aimed to improve the percentage of youth and adults with a SCI to successfully access both post- secondary education and employment and the results showed

that mentoring programmes can be beneficial towards achieving the goals of post-secondary education, employment and community independence for individuals with a SCI.

Outdoor recreation, adaptive sports, health promotion, capacity building and technology aided programs

Three studies (Lundberg et al., 2011; Conway, 2011; Block et al., 2010) reported on effectiveness of adaptive sports, outdoor recreation, health promotion and capacity building programmes for individuals with a SCI and the general results of these studies showed that the above mentioned programmes helped to improve psychological health, improved social relationships, helped individuals with a SCI to reclaim their lives, to gain independent living skills and confidence in their abilities to set and achieve a variety of goals in the areas of education, employment, housing, transportation accessing community resources, participation in sports and leisure as well as in health promotion. These in turn improved their quality of lives and helped them to live successfully in their communities. The implication of the results of the above mentioned programmes is that these are essential to community reintegration especially at client level as they seem to improve self-efficacy, self-esteem and self-regulation of individuals with SCI.

One study (Lancioni et al., 2015) aimed to investigate the effectiveness of technology aided leisure and communication programs for persons with a SCI and post-coma multiple disabilities. These programs focussed on enabling the participants to activate songs, videos, requests, text messages and telephone calls. These options were presented on the computer screen and activated through a small pressure micro switch by the man with a SCI and a special touch screen by post-coma man. The results showed that both participants were successful in managing the programs arranged for them. The implication of these programs to reintegration

is that technology aided programs may be critical to enable persons with multiple disabilities and spinal cord injuries to engage in leisure activities and communication events independently.

6.6 Conclusion

Employment and return to work is regarded an important factor that influence community reintegration following a SCI. Vocational rehabilitation services such supported employment programs can play a major role for gaining employment or return to work following the injuries. Other rehabilitation programs such as mentoring, outdoor recreational and therapeutic adaptive sports programs can improve physical and psychological health of individuals with a SCI. These can promote community independence living skills, promote positive self- efficacy by increasing confidence in abilities to set and achieve goals in the areas of education, employment, housing, transportation, access to community resources and activities. These in turn facilitate community reintegration and improves quality of life for individuals with a SCI.

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Chapter Seven

Integrated Discussion

"It is hard enough to remember my opinions, without also remembering my reasons for them"

Friedrich Nietzsche, 1844-1900, a Germany philosopher

7.1 Introduction

As evident from the first three phases of this study and literature, community reintegration is indeed a complex phenomenon that requires the measurements of more than one aspect. In order to address this complexity, the present study used a multidimensional approach with different phases. Due to the complexity of community reintegration and the other constructs associated with it, such as self-efficacy and quality of life, the first phase of the study attempted to gather baseline information regarding these issues. Psychosocial reintegration, perceived community reintegration and their interaction with self-efficacy and quality of life were measured. In addition, the views and perspectives of other stakeholders such as individuals with a TSCI, caregivers, health professionals and other members representing disabled people in the community were explored to gain a deeper understanding of community reintegration. The study further identified programmes designed to facilitate community reintegration following a SCI. This chapter therefore, provides an integrated discussion of the findings of these three phases that attempted to provide sufficient information to assist in the design of community reintegration programme for individuals who sustained a TSCI in the Cape Metropolitan Area, Western Cape Province, South Africa.

7.2 Integration of findings

In order to design a community reintegration programme for individuals with a TSCI, baseline information regarding community reintegration should be available. Through this approach, the study successfully identified self-reported community reintegration following a TSCI, multiple stakeholders' perspectives regarding community reintegration following a TSCI as well as the programmes addressing community reintegration following a TSCI.

The results of the first phase clearly indicate that both measured psychosocial and perceived community reintegration could be considered as low. These findings are consistent with literature which shows that self-efficacy can positively or negatively influence reintegration into communities following the injury (Miller, 2009) and that low self-efficacy among individuals with SCI maybe be associated with lower quality of life (Middleton et al., 2007) as a positive strong correlation was found between these three constructs.

Employment was found to be a statistically significant variable to reintegration following a TSCI in this study. Individuals that were employed significantly scored higher on psychosocial, perceived community reintegration, self-efficacy and quality of life. However, despite the significance of employment, it was also clear that finding employment following a TSCI is barely possible in South Africa. This is evident in that only 38% of participants were employed and even among those that were employed only 61% were employed on full time basis.

On further examination, the impact of unemployment was evident from the item 9 on the CIM that was endorsed the second least by the participants "*I have something to do in this community during part of my day that is useful and productive*". The other assumption is that lack of employment could mean lack of adequate financial resources. Therefore, individuals with a TSCI could possibly be forced to live in communities that are affordable but not necessarily desirable. This could possibly have been the reason why item 1 on the CIM was endorsed the second least by the study participants *"I feel like part of the community, like I belong here"*. From the discussion above, it is clear that employment have a significant bearing on the low reintegration of individuals with a TSCI. Therefore, the second phase attempted to gain a deeper understanding of how employment and other factors could have influenced reintegration into communities.

The second phase sought the perspectives of multiple stakeholders regarding community reintegration following a TSCI. The discussions with stakeholders shed further light on employment but also highlighted the association with other factors such as transportation. The findings pointed to what could be interpreted as a "catch-22" situation as participants indicated that lack of transport services meant that they cannot get to workplace but on the other hand finding employment seems futile as once they have secured employment the issue of transportation will become a challenge again. *"I would like to get a job but the problem is transport to get to work. Actually I got a job at the day hospital but I could not take it because I cannot get there. I need a hired vehicle to take me there because it is uphill from where I stay and I cannot get there with a wheelchair" (Ana).*

In addition to transportation, issues related to discrimination based on race was also raised. *"I think government is discriminating us due to our race. Because I am a white person I cannot get a job. Most of the job adverts say "only black people must apply". I also need to get ahead in my life but I cannot even send my CV because most of job adverts clearly states that only blacks must apply" (Nick).*

Furthermore, the negative attitude of employers towards individuals with disabilities were also highlighted. *"The employers do not want to employ people with disabilities. Especially people with physical disabilities because they do not want to adjust the work environment in order to meet the needs of disabled people. So I think they should not be any discrimination towards employment opportunities based on any condition including people with disabilities" (RP3).*

All these issues could potentially be associated with the high unemployment rate found in this study. In addition to employment and transportation, other issues such as home and outdoor environments, leisure and recreational facilities, support and relationships, attitudes, systems,

services and policies, as well as self-efficacy and sense of belonging in the communities were also found to have positively and or negatively influenced reintegration into communities following the injury. Therefore, it is clear that the issues influencing community reintegration of individuals with a TSCI highlighted by various stakeholders during the discussion were closely linked to participation domain of the ICF including environmental and personal factors.

The results of the first and second phase pointed to the need of identifying existing programmes addressing community reintegration following a SCI. Thus, the third phase of the study aimed to provide a thorough review of the programmes addressing community reintegration following SCI. The studies reviewed in the third phase again pointed to the fact that gaining meaningful employment is an important factor that influences community reintegration following a TSCI. This was evident in that supported employment and mentoring programmes identified in this phase of the study played a significant role in helping individuals with SCI to gain post-secondary education and employment, promoted leisure and communication opportunities, helped individuals with SCI to achieve community independence and improved their quality of life in general.

In addition to supported employment and mentoring programmes, adaptive sports, outdoor recreation, health promotion and capacity building programmes were also identified at this phase. These programmes were also found to be very important as they generally improved psychological health, social relationships, helped individuals with a SCI to reclaim their lives, gain independent living skills and confidence in their abilities to set and achieve a variety of goals in the areas of education, employment, housing, transportation, accessing community resources as well as participation in sports and leisure activities.

7.3 Conclusion

The integration of the results of the first 3 phases clearly shows that a successful community reintegration programme should be designed targeting three (3) different levels namely: client level, community/society level, as well government/legislative level. These three levels correspond with the participation domain of the ICF as both personal factors such as self-efficacy, sense of belonging into the community and employment status as well as environmental factors that fall under the participation domain of the ICF were identified as factors that influence reintegration into communities following a TSCI. Therefore, based on the results of these three phases, the components to be included in the community reintegration programmes and strategies for the programme was designed and a Delphi technique was used to reach consensus on the components and strategies to be included in the programme to be designed. The details of the Delphi technique and the results of this process are outlined in the next chapter of the study.

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Chapter Eight

Design of a community reintegration programme and consensus

There is no coming of consciousness without pain"

Carl Jung, 1875-1961, Swiss Psychiatrist

Eugene Nizeyimana, Julie Phillips

Abstract

Background: Delphi technique is substantially necessary to reach consensus on a particular subject through a group process involving an interaction between a researcher and a group of identified experts on a specified topic.

Objective: To design and reach consensus on community reintegration programme for individuals who sustained a TSCI in the Cape Metropolitan Area.

Methods: A purposively selected panel of experts in the field of spinal cord injury rehabilitation were approached for their opinions to standardize the content of the programme to be designed. The consensus from the experts was set to 70% or more.

Results: Consensus was reached (100%) on components to be included in the programme. These components included access to employment, education, accessibility to home and community environment, transport, assistive devices/technologies, sports, leisure and recreational facilities. Experts also agreed (100%) that the programme to be designed should target 3 different levels namely: client, societal/community and legislative/governmental levels. Therefore, the strategies to be included in the community reintegration programme were proposed based on above mentioned components targeting the above mentioned three levels. Consensus on the strategies proposed were reached above 70% and the community reintegration programme model was designed based on the agreed strategies at three different levels.

Conclusion: A successful community reintegration programme for individuals with a TSCI should target clients with a TSCI, society/community and legislative/government.

8.1 Introduction

This chapter presents the steps followed in carrying out a Delphi study and consensus reached on components and strategies to be included in community reintegration programme designed. The methodology and procedure used are described. The results of each round of the Delphi will be presented systematically.

8.2 Background

The focus of rehabilitation research in the developed countries has recently been shifted towards community reintegration of individuals of disabilities as they return home from rehabilitation centres. Community reintegration is an essential component of the entire rehabilitation process especially after a TSCI since this intend to occur among young working individuals who have active families and social life (Sekaran et al., 2010).

Community reintegration has been defined as multidimensional construct including reintegration into home like setting, into a social network and reintegration into productive services such as employment, school and voluntary work (Willer et al., 1993). However, despite being considered an important rehabilitation measure, community reintegration following a TSCI has been rarely discussed in South Africa. The existing body of knowledge on community reintegration is largely from developed countries therefore, it is utmost importance to have proper community reintegration programmes that will assist individuals who sustained a TSCI in South Africa to reintegrate back into their communities.

The overall aim of this study is to design a community reintegration programme for individuals who sustained a traumatic spinal cord injury in the Cape Metropolitan Area. Previous chapters

outlined the results of different phases that were done to inform the development of the programme. The programme to be designed focuses on intervention to remove barriers to community reintegration following spinal cord injury. The programme targets client, community/society as well as government/legislative levels. A consensus of opinions from a group of experts in the field of the programme designed had to be reached on about the content of the programme through a Delphi study.

A Delphi technique was originally developed to “obtain the most reliable consensus of opinion of a group of experts by a series of intensive questionnaire interspersed with a controlled feedback” (Ludwig & Starr, 2005). The validity of the resulting judgment of the entire group is typically measured in terms of the explicit "degree of consensus" among the experts (Linstone & Turoff, 2002). What distinguishes the Delphi from an ordinary polling procedure is the feedback of the information gathered from the group and the opportunity of the individuals to modify or refine their judgments based upon their reaction to the collective views of the group (Linstone & Turoff, 2002). Thus, the developed components and strategies to be included in reintegration programme were sent to the experts in the field of spinal cord injury rehabilitation via emails. The aim was to get the most reliable consensus of opinions from this group of experts from the field of spinal cord injury rehabilitation on to components and strategies to be included in the programme designed.

8.3 Methodology

A two round Delphi technique was employed for the present study. Experts in the field of spinal cord injury rehabilitation were approached for their opinions to standardize the content of the programme.

8 .3.1 Procedure

A purposively selected panel of experts was invited to participate in the Delphi study. The experts included Physiotherapists, Occupational therapists, Psychologists, assistive devices technologist and distinguished researchers. These experts were nominated by organizations such as: WHO, ISCoS, ASIA and researchers at the local and international universities who were requested to provide the names of expertise in the field of spinal cord injury rehabilitation who were willing to participate in the study.

As a Delphi technique does not require the physical presence of the group members, an invitation to participate in the study was sent via email to all identified/nominated individuals. An information sheet (Appendix 7) outlining the purpose of the study and a consent form (Appendix 8) were included. Informed consent was requested via-email from twenty (20) experts that fit inclusion criteria to participate in the Delphi study. Fifteen (15) of the invited experts consented to the study marking an initial response rate of 75%.

A questionnaire was developed and reviewed by 2 independent researchers for the applicability of the questions (Appendix 9a). The first section requested demographic information of participants, including age, gender, highest level of qualification, current profession, county of residence, number of years' experience in spinal cord injury rehabilitation and the role in the SCI rehabilitation.

Three (3) open- ended questions were included in the section two. These questions are:

1. In your opinion what does community reintegration following spinal cord injury mean?

2. In your opinion, what components should be included in a community reintegration programme following spinal cord injury?

3. In your opinion, who are the role player/stakeholders that should be included when designing a community reintegration programme following spinal cord injury? And why?

Twelve (12) participants returned the questionnaire within 5 weeks resulting in an 80% response rate. The description of the participants is outlined in Table 8.1. The consented participants had a mean age of 50. 58 years (SD= 10.1) and 16.42 (SD= 8. 24) years of work experience in spinal cord injury rehabilitation as illustrated in Table 8.1 below.

Table 8.1. Demographic Characteristics of Panel of Experts (n=12)

ID Code	Age years	Gender	Highest level of Qualification	Country of Residence	Current Profession	Years of Experience	Role in SCI Rehabilitation
1	64	Female	PhD (Physiotherapy)	United State of America	Physiotherapist	10 years	Physiotherapist and Researcher
2	50	Female	PhD (Psychology)	United State of America	Clinical Psychologist	20 years	Clinical Psychologist and researcher
3	54	Female	PhD (Physiotherapy)	Australia	Clinical supervisor and Researcher	20 years	Social science Researcher
4	34	Female	PhD (Physiotherapy)	South Africa	Physiotherapy lecture and Researcher	7 years	Clinical rehabilitation physiotherapist
5	65	Female	PhD (Physiotherapy)	Sweden	Physiotherapist	5 years	Research supervisor and Researcher
6	52	Female	MSC (Physiotherapy)	South Africa	Clinical supervisor	30 years	Clinical rehabilitation physiotherapist
7	50	Female	MSC (Physiotherapy)	New Zealand	Physiotherapist	26 years	Community based rehabilitation
8	51	Male	PHD (Occupational therapy)	South Africa	Occupational therapist lecturer and researcher	10 years	Vocational rehabilitation
9	53	Female	PHD (Occupational therapist)	New Zealand	Occupational therapist	26 years	Researcher
10	30	Male	PHD (Physiotherapy)	South Africa	Lecturer and researcher	9 years	Researcher
11	55	Male	MSC (Orthothist)	United Kingdom	Assistive devices consultant	15 years	Consultant (Assistive technology)
12	49	Male	PHD (Orthotist)	Sweden	Assistive devices consultant	20 years	Consultant (Assistive technology)

8.4 Results of the first round of the Delphi study

The response rate of the round one was 80% as only twelve (12) participants among those fifteen (15) that had initially consented to participate completed and returned the questionnaire within 5 weeks. A summary of the responses according to emerging themes from the three (3) open-ended questionnaire is presented in the tabular format below.

The emerging themes with regards to community reintegration following traumatic spinal cord injuries included: "being able to live independently in the community after the injury, having access to employment and education, fulfilling the social role and having family, friends and societal support" as illustrated in table 8.2.

Table 8.2. Meaning of community reintegration following spinal cord injury according to the experts (n=12)

Emerging themes	n (%)
Able to live independently in the community	12 (100)
Full participation in social role	12 (100)
Able to gain employment	12 (100)
Access to education	12 (100)
Having family, friends and societal support	11 (91.66)

The components identified by experts that should be included in the community reintegration programme following a traumatic spinal cord injury included: "accessibility to homes,

community and work place environments, employment, availability of transport, assistive technologies and recreational facilities".

These are summarised in table 8.3

Table 8.3. Components that should be included in a community reintegration following a traumatic spinal cord injuries according to the experts (n=12)

Components	**n (%)**
Employment	**12 (100)**
Education	**12 (100)**
Accessibility	**12 (100)**
❖ Home environment	12 (100
❖ Community environment	12 (100)
❖ Work place environment	11(91.66)
Availability	**12 (100)**
❖ Transport	12 (100)
❖ Assistive devices/ technology	12 (100)
❖ Recreational facilities	12 (100)
❖ Peer support systems	11 (91.66)
❖ Counselling services	9 (75.00)

With regards to role player/stakeholders that should be included when designing a community reintegration programme following a TSCI, several suggestions were made. As summarised in table 8.4, these included persons with spinal cord injury, different health professionals, families and caregivers to mention but few.

Table 8.4. Role player/stakeholders that should be included when designing a community reintegration programme following spinal cord injuries (n=12)

Role player/stakeholders	**n (%)**
Individuals with spinal cord injuries	**12 (100)**
Multidisciplinary team	**12 (100)**
❖ Physicians	12 (100)
❖ Physiotherapists	12 (100)
❖ Occupational Therapists	12 (100)
❖ Psychologists	11(91.66)
❖ Social workers	10(83.33)
❖ Vocational rehabilitation therapists	10 (83.33)
❖ Nurses	9 (75.00)
❖ Assistive technology specialists	8 (66.66)
❖ Community based therapists	8 (66.66)
Families and care givers	**12 (100)**
Policy makers	**11(91.66)**
Employers	**11(91.66)**
Community leaders	**9 (75.00)**
Religious leaders	**8 (66.66)**
Peer support/mentors	**8 (66.66)**
Leisure and recreational workers	**8 (66.66)**
School leaders	**8 (66.66)**
Business people	**7 (58.33)**

8.5 Second round of the study

Based on the emerging themes, from the responses of the first round of the Delphi study, the strategies to be included in the community reintegration programme was designed (Appendix 9b) and sent to the experts as the second round of the Delphi study for their opinions.

Ten (10) out of twelve (12) experts that participated in round 1 responded to round 2 Delphi study making it 80% response rate. For an item to be included as a strategy for a community reintegration programme, consensus from the experts was set to 70% or more (Mc Kenna & Hasson, 2002).

From the results of the first round, it was very clear that the programme designed should target three different levels namely: client level, community/societal level, governmental/legislative level. Therefore, the strategies were designed targeting the above mentioned levels. The purpose of the second round was to reach a consensus on which levels the programme designed should target and what strategies should be included in the programme at each level. Table 8.5 illustrates the results of round two of the Delphi study.

Table 8.5 consensus on community reintegration levels and the strategies that should be included in the programme designed.

Community reintegration should be designed at the following levels	
Items	**n (%)**
• Client level	10(100)
• Societal/community level	10(100)
• Governmental/legislative level	10(100)

- **Strategies at client level should include:**

• Teach the clients with a TSCI how to change negative self-perception and improve their self-efficacy/esteem	9(90)
• Encourage self-regulation of individuals with a TSCI	9(90)
• Encourage personal motivation of individuals with a TSCI	9(90)
• Encourage goal setting	9(90)
• Counselling of SCI injury clients to accept their limitations and their consequences	8(80)
• Help individuals with a TSCI to enhance acceptance and develop new copping strategies to overcome the challenges/barriers	9(90)
• Educate families/caregivers about the injuries of their members and how they can assist them to overcome challenges/barriers	9(90)

- **Strategies at community/societal/ level should include:**

➢ **Strategies for home reintegration:**

• Teach clients and their families/ care givers the new strategies to negotiate residential barriers	10(100)
• Make house adaptation and modification to facilitate clients with TSCI to accomplish their needs of daily living	10(100)
• Design and provide disability friendly housing to individuals with a TSCI	9(90)
• Involve individuals with a TSCI in the process of designing disability Friendly housing	9(90)

➢ **Strategies at both home and community reintegration:**

❖ **To improve Attitude**

- Sensitisation workshops to change family/friends and caregiver's negative Attitudes towards individuals with a TSCI 10(100)
- Sensitisation workshops to change wider community's negative attitudes towards individuals with a TSCI 10(100)
- Sensitisation workshops to change heath professionals' negative attitudes towards individuals with a TSCI 7(70)

❖ **To improve sports/leisure and recreation services**

- Involve individuals with a TSCI in design of sports, leisure and recreation Facilities 10(100)
- Include adaptive sports, leisure and recreational programmes as part of rehabilitation process for individuals with a TSCI 10(100)
- Provide assistive devices/technologies that will facilitate individuals with a TSCI to participate in adaptive sports leisure and recreation 10(100)
- Include staff that is trained specifically on disability awareness and adapted physical activity in clubs, leisure and recreational facilities 10(100)
- Make information available to individuals with a TSCI about recreational facilities 10(100)
- Encourage health clubs and recreational facilities to make adaptions of recreation space and equipment to meet individuals with a TSCI's needs 10(100)

❖ **To improve transport services**

- Provide special transport designed specifically for individuals with a TSCI 10(100)
- Provide tall free call centres for booking special transport 7(70)
- Provide lift-equipped and trolley bus on major roots 9(90)
- Provide portable bridge piece in each bus 9(90)
- Provide easily reachable grab bars in the buses for boarding 9(90)
- Make every bus a wheelchair friendly on major routes 10(100)

- Make each platform at train station to be a wheelchair accessible 10(100)
- At least one or two cars in each train should be accessible to wheelchair users 10(100)
- Parking for individuals with disabilities should be available 10(100)
- Make all airport terminals accessible by individuals with disabilities 10(100)

❖ **To improve services on assistive devices/technology**

- Ensure individuals with a TSCI are involved in all stages of assistive devices/ technologies provision 10(100)
- Ensure that assistive devices/technologies are available to everyone with identified needs 10(100)
- Ensure affordability of assistive devices/technologies to all in need 10(100)
- Ensure that assistive device/technology are adapted according to individual's needs 10(100)
- Ensure that all relevant resources, programmes and services required for provision of assistive devices/technologies are available to all individuals with a TSCI 10(100)
- Provide training in mobility skills to individuals with a TSCI and specialist staff working with them 10(100)
- Ensure modification of physical environment to facilitate the use of mobility devices 10(100)
- All services related to the provision of assistive devices/technologies should be available to all individuals with a TSCI 10(100)
- Service providers to improve marketing strategies of assistive devices/ technologies available to create more awareness 10(100)
- Follow-up services should be part of rehabilitation process to ensure continuity of care 10(100)

❖ **To improve education**

- Ensure that persons with a TSCI are included in all education levels 10(100)
- Provide support to individuals with a TSCI who have got personal talents and creativity 10(100)

- Provide accessible accommodation at all educational institutions 10(100)
- Provide support to individuals with a TSCI to complete education in the field of their choice 10(100)

❖ **To improve employment**

- Vocational rehabilitation should be a compulsory part of rehabilitation process 10(100)
- Supported employment programme should be part of rehabilitation process for individuals with a TSCI 10(100)
- Educate all employers in order to change negative attitudes towards persons with a STCI 10(100)
- Educate co-workers in order to change negative attitudes towards persons with a TSCI 9(90)
- Employers should provide work place accommodation for individuals with a TSCI 9(90)
- Employer should provide transport to employee with a TSCI as part of remuneration package 7(70)

▪ **Strategies at government level should include:**

➢ **clear policies on inclusion of individuals with a TSCI and persons with a TSCI should be included at all levels of these policies making in all areas that affect them such as the following:**

- Access to medical and rehabilitation services including the provision of assistive/technologies 10(100)
- Housing/accommodation 10(100)
- Transport services 10(100)
- Education 10(100)
- Employment 10(100)
- Sports, leisure and recreation 10(100)

8.6 Discussion

In the second round of the Delphi study, consensus was reached regarding the intended programme. All participants n=10(100%) agreed that the programme to be designed should target the three levels that are: client, community/societal and government/legislative levels.

Nighty percent (90%) of participants agreed that strategies at client level should include: Teaching the client with a TSCI how to change self-perception and improve their self-efficacy, encourage self-regulation (i.e. their ability to monitor and control behaviour and alter them in accordance with the demands of the situation), encourage personal motivation (i.e. their ability to do what needs to be done without the influence of the other people or situations. Experts also agreed that individuals with a TSCI should be encouraged to set goals that are specific, attainable and take steps to achieve those goals. Furthermore, it was agreed upon that individuals with a TSCI should enhance acceptance and develop new coping strategies to overcome the challenges/barriers. Experts agreed that family members and caregivers of individuals with a TSCI should be educated on how they can assist their members to overcome the challenges/barriers that they might encounter. About eighty percent (80%) of the experts agreed that individuals with a TSCI should be counselled and be encouraged to accept their limitations and their consequences.

While consensus was reached on the proposed strategies at client level of reintegration, some of the experts also had additional comments to the strategies proposed. One of the expert felt that reintegration programme at client level would vary from client to client. This is highlighted in the comment bellow.” *The tailoring of the package of support at the client level would vary from client to client*”.

Another expert felt that teaching self-efficacy or acceptance might be difficult and the expert suggested that it is better to work with an individual through those aspects to enhance self-management. This is highlighted in the following comment. "*I would only say that while self-regulation is a very useful skill, you also do not want to victim blame and make it all the responsibility of a person with disability to do all the adapting*". *You would hope that at least the community should also meet them half way with the empathy and awareness of how they really do face more social and physical barriers.*

Strategies at the community level included improving residential and community reintegration, improving attitude of general population, sports/leisure and recreation services, transport services, assistive devices/technologies, education and employment.

At residential level, all participants (100%) agreed that adaptation/modification of the houses should be made to facilitate clients with a TSCI to accomplish their needs of daily living. They also agreed that clients with a TSCI, their families and caregivers should be thought new strategies to negotiate residential barrier. About ninety percent (90%) of the experts agreed upon that disability friendly housing should be designed and that individuals with a TSCI should be involved in the process of designing those houses.

Regarding the attitudes of the general population towards individuals with a TSCI, all participants (100%) agreed that there should be sensitisation workshops to change family/caregivers, health professionals and the wider community's negative attitudes towards individuals with a TSCI.

In order to improve sports/leisure and recreation for individuals with a TSCI, all participants (100%) agreed that individuals with a TSCI should be involved in the designing process of sports/leisure and recreation facilities. They also agreed that sports/leisure and recreational

programmes should be part of rehabilitation process for individuals with a TSCI. Provision of assistive devices/technologies that will facilitate individuals with a TSCI to participate in sports/leisure and recreation, they agreed that staff who is trained specifically on disability awareness and adapted physical activities should be included in clubs, leisure and recreational facilities, information about recreational facilities that are accessible by persons with disabilities should be available to individuals with a TSCI as well as encouraging health clubs/leisure and recreation facility owners to make adaptations and recreation space and equipment to meet persons with a TSCI's needs.

Although all participants agreed on the strategies to improve sports/leisure and recreation, one participant had an additional comment on this component of reintegration emphasising its health benefits for all. However, the expert also felt that this should be the individual's choice as not all persons with disabilities may like sports. This is emphasized in the comment below.

"Sport is an enormously useful way to encourage social participation for persons with SCI. They build social networks and increase healthy ways of living and decrease loneliness and social isolation which is very detrimental to health of any person, disabled or not. However, one must be mindful that not everyone likes sports. What is the right kind of group to build to support, for example, a woman with a SCI who has not interested in sports at all? They need to be thought about too. And the best way to find out what these other groups would like to do is to ask them and let them, not some medical professional guide the process. The person themselves know a lot about what is interesting to them and would help get back into the community and daily life. I think it is critical to have the voice of individuals living the experience of disability be the ones who define what opportunities are best for them".

On strategies to improve transport services, all participants (100%) agreed that there should be special transport designed specifically for individuals with a TSCI and about seventy percent (70%) agreed that there should be a tall free call centres for booking of special transport. All participants also agreed that all buses on major roots should be a wheelchair friendly, each platform at the train station to be a wheelchair accessible, and at least one or two cars in each train to be accessible with wheelchairs users. They also agreed that parking designated for individuals with disabilities should be available and all airports terminals should be accessible by individuals with disabilities.

About ninety percent (90%) of the participants agreed that there should be a lift-equipped and trolleys buses and a portable bridge piece and grab bars in the buses for easy boarding.

Although above strategies were perceived by all participants to be good strategies, one of the participant felt that these might take time to be put into practice as indicated in the following comment. *"The United Nations Convention on the Rights of Persons with Disabilities (which was signed by South Africa) includes equitable access to the environment for all people. This will take time to be put into practice, but until we begin addressing practice as per the above strategies, people with SCI will not be able to access their environment/community".*

Regarding assistive devices/technologies, all participants (100%) agreed that individuals with a TSCI should be involved in all stages of assistive devices/technologies provision. They also agreed that assistive devices/technologies should be adapted according to the individual needs, made available and affordable to all in a need of them, physical environment should be modified to facilitate the use of mobility devices, service providers should improve marketing strategies to create more awareness of available assistive devices/strategies and that follow-up services should be part of rehabilitation process to ensure the continuity of care.

With regards to the strategies to improve education, all participants (100%) agreed that individuals with a TSCI should be included in all educational levels, (i.e. primary, secondary and tertiary education, vocational training, adult education and life- long learning). They also agreed that in individuals with a TSCI should have accessible accomodation at all educational institutions and get all the support needed to complete their education in the field of their choices. However, one of the participants felt that individuals with a TSCI should not have the rights to education beyond that of other people in the society as stated in the following comment "*I agree that all people with disabilities have the right to education, but not beyond that extended to other people in the society".*

Regarding the strategies to improve the employment, all participants (100%) agreed that vocational rehabilitation should be a compulsory part of rehabilitation process, supported employment programmes should be part of rehabilitation process and employers should be educated in order to change negative attitudes towards individuals with a TSCI. About ninety percent (90%) of the participants agreed that co-workers should be educated to change negative attitude towards individuals with a TSCI and that employers should provide accommodation for individuals with a TSCI at work place. Seventy percent (70%) agreed that employers should provide transport to employees with a TSCI as part of remuneration package.

Regarding strategies at the government/ legislative level, all participants (100%) agreed upon that there should be clear policies on inclusion of individuals with a TSCI and that individuals with a TSCI should be included at all levels of those policies making in all areas that affect them such as: access to medical and rehabilitation services, housing/ accommodation, transport services, education and employment as well as sports/leisure and recreation.

8.7 Proposed community reintegration program

From the results of the Delphi study, a community reintegration model was designed. The programme designed aims to deliver coordinated and integrated services through three levels (client, community and government levels) in order to achieve a successful community reintegration.

Client level: The first level of intervention is directed to clients with a TSCI. To encourage full participation into the communities, support and education of the clients of a TSCI is needed to facilitate them to overcome the challenges and barriers that they might face with their new body in the changed world. Through counselling clients with TSCI can be helped to change negative self- perception and encourage positive self- efficacy, self-regulation and personal motivation and goal setting. In addition, encouraging them to enhance acceptance will help them to accept their limitations and their consequences then develop new coping strategies to overcome day today's challenges.

Community/ Societal level: the second level of intervention target the community. A coordinated collaboration of all stakeholders is needed in order to remove all barriers face by the individuals with a TSCI in their day today's lives. Through a coordinated collaboration of multiple stakeholders including individuals with a TSCI, multidisciplinary rehabilitation team, families and caregivers, policy makers, employers, community leaders, peer support/ mentors, business people/service providers, school leaders, religious leaders, leisure and recreational workers all barriers to participation related to natural environment, human made changes to the environment, products and technologies, support and relationship, attitudes, services, systems and policies can be removed.

Government/ legislative level: at this level, clear policies on inclusion of individuals with a TSCI are needed. Individuals with a TSCI should be included at all levels of policy making in all areas that affect them such as: access to medical and rehabilitation services including access to assistive devices/technologies, access to housing and accommodation, transport services, education and employment, as well as sports, leisure and recreation. Multiple stakeholders should engage with government at this level to promote advocacy and lobbing, monitor policy changes, identify and develop findings streams and mobilise support constituencies.

Figure 8.1 illustrates a proposed community reintegration program model.

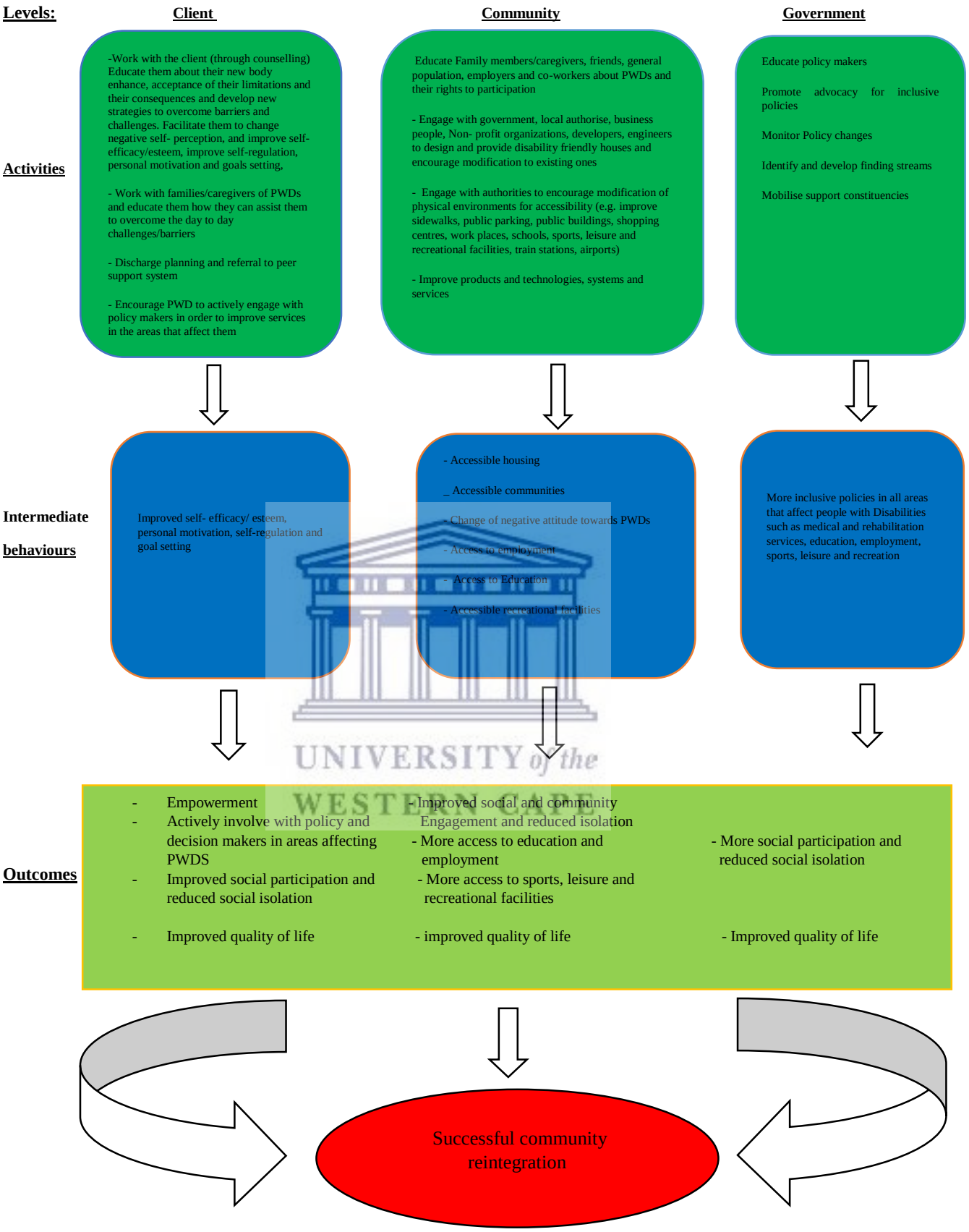

Figure 8.1 Community reintegration program model

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Chapter Nine

Summary, Conclusion and recommendations

"Endurance and to be able to endure is the first lesson a child should learn because it is the one they will most need to know"

Jean Jacques Rousseau (1712- 178), Swiss political philosopher and essayist

9.1 Summary

The life of individuals who sustain a TSCI changes dramatically. The ultimate aim of rehabilitation for individuals with disabilities is a successful reintegration into communities following the injury. A definition pertaining to community reintegration includes a common feature such as: residential setting, an appropriate social network, community activities and accepting responsibilities as an equal member of the society, productive activities such as employment, education and voluntary work as well as interactive relationships with family members, friends and the larger communities. Despite this variable importance in rehabilitation of individuals with disabilities, community reintegration following a TSCI has been rarely discussed in South Africa.

The main aim of this study was to design a community reintegration programme for individuals who sustained a TSCI in the cape Metropolitan Area, western Cape Province, South Africa. In order to achieve this aim, the current study used a milt-dimensional approach and was conducted through four (4) different phases.

The first phase aimed to determine self-reported community reintegration of individuals who sustained a TSCI. Through a multi-dimensional approach, this phase successfully identified, psychosocial, perceived community reintegration, self-efficacy and quality of life of individuals who sustained a TSCI.

The overall sample of this phase consisted of 108 individuals with a TSCI ranging from 19-71 years old (M= 37.2; SD = 12.2) who were living in the community and were between 1 and 35 years after the injury (M= 10.24; SD= 9.1). The majority of the total sample were males 77.8% (n=84) and 22.2% (n= 24) were females. Almost half 45.4% (n= 49) were blacks and almost two thirds 62% (n= 67) of the sample were unemployed. Regarding the level of the injury, the majority of participants 58.3% (n= 63) were paraplegic, while 41.7% (n= 45) were tetra/

quadriplegic. The main cause of injury for the study sample was motor vehicle accidents 43.5% (n=47) although violence causes were not infrequent 38% (n=41).

Both psychosocial and perceived community reintegration were moderately low. Employment appeared to be a statistically significant variable influencing community reintegration following a TSCI as individuals that were employed scored higher on both psychosocial, perceived community reintegration, self-efficacy and quality of life. However, the study also highlighted that finding employment after sustaining a TSCI is barely possible in South Africa. Other demographic characteristics that were significantly associated with reintegration into communities included race, gender, type of accommodation and level of the injury. Black participants significantly scored lower in psychosocial reintegration and quality life compared to whites and coloureds respectively. Individuals that lived in informal dwellings/shacks significantly scored lower in psychosocial and perceived community reintegration as well as quality of live compared to individuals who lived in formal houses and nursing homes. Female participants significantly scored lower in both self-efficacy and quality of life compared to male counterparts, and individuals with paraplegia significantly scored lower compared to those with tetra/quadriplegia. The final results of this phase of the study demonstrated a strong positive correlation between community reintegration, self-efficacy and quality of life.

In order to gain a deeper understanding on how employment and other factors could have influenced reintegration into communities following a TSCI, the second phase of the study that aimed to explore the multiple stakeholders' perspectives regarding community reintegration following a TSCI was conducted through in-depth face to face interviews. A total of 28 participants from different stakeholder groups participated in this phase of the study.

Stakeholders included people with a TSCI that were purposively selected from phase one (n=11), caregivers (n=6), rehabilitation professionals (n=3), members representing disabled people's organizations (n=5), members of quad-para association South Africa (n=2), as well as a member representing transportation services of individuals with disabilities (n=1).The findings of this phase indicated that there was a link between employment and others issues such as transportation and employer's negative attitudes towards individuals with a TSCI. In addition, home and outdoor environments, leisure and recreational facilities, support and relationships, attitudes, systems, services and policies, self-efficacy, sense of belonging in the communities were also found to have positively and or negatively influenced reintegration into communities following the injury. On closer look at the findings of the second phase of this study, it is evident that the issues influencing community reintegration of individuals with a TSCI highlighted by various stakeholders during the discussion were closely linked to participation domain of the ICF including environmental and personal factors.

The results of the first and second phase pointed to the need to identify existing programmes that address community reintegration following the injury leading to the third phase of the study that aimed to provide a thorough review of the programmes addressing community reintegration following SCI. The review at this phase identified 10 studies that met the inclusion criteria. The studies reviewed pointed to the fact that gaining meaningful employment is an important factor that influences community reintegration following a TSCI. This was evident in that general vocational rehabilitation, supported employment and mentoring programmes identified in this phase played a significant role in helping individuals with SCI who participated in these programs to gain post- secondary education and employment. The programs further promoted leisure and communication opportunities, they helped individuals with a SCI to achieve community independence and improved their quality of life in general.

In addition to above mentioned programmes, adaptive sports, outdoor recreation, health promotion and capacity building programmes were also identified as essential components to reintegration as they generally improved psychological health, social relationships, helped individuals with a SCI to reclaim their lives, gain independent living skills and confidence in their abilities to set and achieve a variety of goals in the areas of education, employment, housing, transportation, accessing community resources as well as participation in supports and leisure activities.

The integration of the results of the first 3 phases clearly pointed to the fact that a successful community reintegration programme should be designed targeting three (3) different levels namely: client, community/society, as well government/legislative levels. This was event in that the factors which influenced community reintegration following a TSCI were closely linked to the ICF domain of participation including both environmental and personal factors. Therefore, based on the results of these three phases, the components and strategies to be included in the community reintegration programme following a TSCI were proposed and consensus was obtained through a Delphi study that formed the fourth and final phase of the study. The components comprising a community reintegration programme were: access to both home and outdoor environment, employment, education, transportation, sports and recreational facilities, assistive devices/technologies, attitudes and counselling services. The strategies for the programme to be designed were then based on the above mentioned components. The details of the Delphi technique and the results of this process are outlined in the chapter eight of the study.

9.2 Conclusion

Reintegration into communities following a TSCI was relatively low in this study. Employment appears to be a significant variable influencing reintegration into communities following a TSCI. However, it is also evident that finding employment after a TSCI is barely possible in South Africa. In addition to employment, other issues such as transportation, home and outdoor environments, leisure and recreational facilities, support and relationships, attitudes, systems, services and policies, self-efficacy, sense of belonging in the communities were also found to have influenced reintegration into communities following the injury. On closer look at the above mentioned factors, it is evident that the issues influencing community reintegration of individuals with a TSCI were closely linked to participation domain of the ICF including environmental and personal factors. The results of this study also pointed to the fact that general vocational rehabilitation and supported employment programs played a major role by facilitating individuals with a SCI to gain post-secondary education, employment or return to work following the injury. Other rehabilitation programs such as mentoring, outdoor recreation and therapeutic adaptive sports programs were also found to be essential as they improved physical and psychological health of individuals with a SCI. These programs also promoted community independence living skills, as well as positive self- efficacy by increasing confidence in abilities to set and achieve goals in the areas of education, employment, housing, transportation, access to community resources and activities. These in turn facilitated community reintegration and improved quality of life for individuals with a SCI. Therefore, it is very clear that a successful community reintegration programme should target three different levels namely: client, community/society and government/legislative levels.

9.3 Recommendations

The results of this study indicated that reintegration into communities following a TSCI was moderately low and a number of factors and programmes that influenced reintegration were highlighted. Therefore, the recommendations are given based on the study findings.

- Factors influencing community reintegration of individuals with a TSCI were closely related to the ICF domain of participation including both personal and environmental factors. This clearly shows that rehabilitation professionals working with individuals with a TSCI should be client oriented and try to identify and address the specific needs of each individual in order to facilitate a successful reintegration into communities following the injury.

- Employment was found to be a statistically significant variable influencing reintegration into communities following a TSCI in this study. Individuals that were employment scored higher in psychosocial, perceived community reintegration, self-efficacy and quality of life. However, it was also clear that finding employment after sustaining a TSCI in South Africa is barely possible as close to two third of the participants were unemployed in this study. Therefore, government, private sectors and Non-profit organizations should work together and offer appropriate employment opportunities for individuals with a TSCI. They should also provide alternating skill training to individuals who are unable to return to their previous jobs due to the nature of the injury and the types of the jobs that they were doing prior to the injury in order facilitate more choices of employment options after the injury.

- Rehabilitation professionals should also become active role players in multi-sectoral collaboration and policy making and implementation to help increase levels of (re)employment of individuals with a TSCI. Rehabilitation team should be more involved with the potential employers and help them to change negative attitudes towards individuals with a TSCI and disabilities in general.

- Lack of an appropriate transport was also found to be a major barrier to community engagement and productive reintegration as some individuals did not want to seek employment knowing that there will not have access to transport to take them to work. It also became evident that in some cases participants could sometime skip schools, miss medical appointments due to lack of transport. Negative attitudes towards individuals with a TSCI from people in transport industries more especially taxi drivers further complicated the access to transportation. Therefore, government, private sectors and non-profit organisations should work together and offer disability friendly public transportation facilities to facilitate individuals with a TSCI to return to their education, employment and facilitate their engagement in the social life activities. Furthermore, general population especially taxi drivers need to be educated and be helped to change the negative attitudes towards individuals with disabilities including those with a TSCI.

- The results of this study shows that individuals who sustain a TSCI in South Africa face the unique challenges due to social economic inequalities. Individuals who lived in informal dwellings/shack were found to be less integrated compared to those that lived in formal houses and nursing homes respectively. Lack of the adequate space in

their homes were identified as the major barriers to reintegration. In this case, some of the participants were forced to leave their homes to nursing homes in search of comfort against their will. This is direct contradiction to the Article 19 of the Convention on the Right of Persons with Disabilities that emphasizes the importance of granting individuals with disabilities the opportunities to choose their place of residence and where and with whom they live on an equal basis with others and that they are not obliged to live in a particular living arrangements. Therefore, South African government with other stakeholders such as private institutions and non-profit organizations should work together to increase the number of accessible housing and encourage associations of people with disabilities, local authorities and housing cooperatives to work with developers to design and provide disability friendly housing with enough space, accessible bathrooms, kitchens, living rooms for individuals with a TSCI to improve their self-care and facilitate their residential and community living life at large. In addition to accessible housing, modification of existing outdoor environment, and creation of new disability friendly environment is of paramount to facilitate community engagement for individuals with a TSCI.

- In the scoping literature review section of this study, it was evident that general vocational rehabilitation, supported employment and mentoring programs were beneficial as individuals with a SCI that attended these programs were able to gain post-secondary education and employment. Therefore, Rehabilitation professionals should emphasize on Vocational rehabilitation and supported employment programs in order to facilitate individuals with a TSCI to gain education and employment following the injury.

- It was also evident that individuals with a SCI who participated in other different type of programmes such as sports, leisure and adaptive outdoor recreation programmes reported numerous befits from attending these programmes. Individuals with a SCI who participated in these programmes reported improvement in both physical and psychological health, improved perceived self-efficacy and assisted individuals with a SCI to gain confidence and discover themselves which in turn enabled them to get out there and reclaim their lives. These programmes further reduced social isolation, helped individuals with a SCI to learn from their peers, gain knowledge and new skills that in turn provided them with opportunities to build confidence and learn more about the new-self (i.e. their new body and their new life following a SCI). Therefore, rehabilitation professionals should include adaptive outdoor sports, leisure and recreation activities during rehabilitation process for individuals with a TSCI. The collaborations between different government sectors such as health departments, sports and recreation departments, private sectors as well as non-profit organizations should assist in these process.

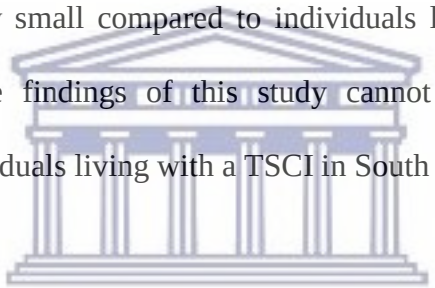
- The entrepreneurs, and other business companies should also work in collaboration with government and other non-governmental departments and develop special and affordable assistive devices/technologies that will facilitate individuals with a TSCI to participate in different type of outdoor sports, leisure and recreation activities.

Limitations of the study

As for all research, there a number of limitations to this study.

- This was a self- reported study. In self-reported studies, participants may exaggerate their responses in order to make their situation seem worse or they may under-report the severity and the frequency of a problem. Therefore, the results of this study should be interpreted with caution.

- Although the sample size was adequate for analytical procedures employed, the sample (n=108) was relatively small compared to individuals living with a TSCI in South Africa. Therefore, the findings of this study cannot be generalized to be true representative of individuals living with a TSCI in South Africa.



- The second phase of the study aimed to explore the multiple stakeholders' perspectives regarding community reintegration following a TSCI. However, some of the stakeholders were underrepresented in this study. For example, only one person represented transportation services, two persons represented members of Quad-Para association of South Africa and only 3 persons represented rehabilitation professionals. Therefore, their views might not have been the representative of all stakeholders in these categories.

- The study used regional data (Cape Metropolitan Area only). Therefore, the results of this study regarding self-reported community reintegration and the views of different stakeholders regarding community reintegration following a TSCI cannot be generalised to be a representative of individuals living with a traumatic spinal cord injury and other stakeholders in South Africa.

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UNIVERSITY of the WESTERN CAPE

OFFICE OF THE DEAN **Appendix 1**

DEPARTMENT OF RESEARCH DEVELOPMENT

08 June 2015

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by: Mr E Nizeyimana (Physiotherapy)

Research Project: Designing a community reintegration programme for individuals with traumatic spinal cord injuries in the Cape Metropole Area.

Registration no: **15/4/51**

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

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

Ms Patricia Josias

Research Ethics Committee Officer

University of the Western Cape
Private Bag X17, Bellville 7535, South Africa T: +27 21 959 2988/2948. F: +27 21 959 3170

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Appendix 2a

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2542, Fax: 27 21-959 1217

E-mail: 2469608@uwc.ac.za

The Director **15th August, 2015**

Quad-Para Association of South Africa

Western Cape

P.O Box 729, Durbanville 7550

Dear Madam/Sir,

RE: Request to access the database for research purpose

My name is Eugene Nizeyimana, I am currently doing a PhD degree program in physiotherapy at the University of the Western Cape, South Africa.

I am expected to carry out a research project as partial fulfilment of the requirements for doctor of philosophy in physiotherapy. The title of my research is:

"Designing a community reintegration programme for individuals who sustained a traumatic spinal cord injury in the Cape Metropolitan Area"

I kindly request the permission to access your database in order to carry out this research project. It is hoped that the results of the study will serve as baseline information to developing the future intervention strategies and policies by all stakeholders such as individuals with a traumatic spinal cord injury, family/caregivers, community members, employers, rehabilitation professionals and policy makers at different levels on community and social reintegration following a traumatic spinal cord injury.

Yours faithfully

Eugene Nizeyimana

Prof. Julie Phillips

Research supervisor

Appendix 2b

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Private Bag X 17, Bellville 7535, South Africa

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

E-mail: 2469608@uwc.ac.za

The Director **15th August, 2015**

Cheshire homes

18 Corsair Rd, Tijgerhof

Cape Town, 7441

Dear Madam/Sir,

RE: Request to carry out a research in your institutions

My name is Eugene Nizeyimana, I am currently doing a PhD degree program in physiotherapy at the University of the Western Cape, South Africa.

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Yours faithfully

Eugene Nizeyimana

Prof. Julie Phillips

Research supervisor

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E-mail: 2469608@uwc.ac.za

The Director **15th August, 2015**

Signa Academy

13 Main Road, Newlands

Cape Town, 7700

Dear Madam/Sir,

RE: Request to carry out a research in your institution

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Yours faithfully

Eugene Nizeyimana

Prof. Julie Phillips

Research supervisor

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INFORMATION SHEET: Clients with a TSCI

Project Title: ***Designing a community reintegration programme for individuals with traumatic spinal cord injury in the Cape Metropolitan Area.***

What is this study about?

This is a research project being conducted by **Eugene Nizeyimana** at the University of the Western Cape. We are inviting you to participate in this research project because you are a suitable candidate. The purpose of this research project is to come up with possible community reintegration programme for individuals who sustained spinal cord injury in South Africa. Reintegration into community life following spinal cord injury is considered an important goal of rehabilitation as this has been positively associated with quality of life, self- esteem and life satisfaction. Despite being and important goal of rehabilitation, community reintegration has been rarely discussed in South Africa. Therefore, there is a need to design a community reintegration programme for individuals who sustained spinal cord injury in South Africa.

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

You will be asked to provide basic information about your reintegration back into your community since the time you returned from the rehabilitation centre. The study is conducted in the Cape Metropolitan Area in South Africa.

Would my participation in this study be kept confidential?

We will do our best to keep your personal information confidential. To help protect your Confidentiality your name and other vital information provided will be coded. Details of any Information provided will be kept strictly confidential. Data collected will be kept in a pass worded computer and other saving devices. If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

What are the risks of this research?
There are no known risks associated with participating in this research project.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about spinal cord rehabilitation process particularly community reintegration following the injury and it will enable the researcher to design a community reintegration programme for these individuals. We hope that, in the future, other people might benefit from this study through improved understanding of reintegration into communities following spinal cord injury.

Describe the anticipated benefits to science or society expected from the research, if any.

It is anticipated that the outcome of this study will assist in the design of an appropriate community reintegration programme for individuals who sustained spinal cord injury in South Africa.

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

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

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

You will be referred to an appropriate health facility should there be a need for referral during the course of the study.

What if I have questions?

This research is being conducted by Eugene Nizeyimana, Department of Physiotherapy, University of the Western Cape. If you have any questions about the research study itself, please contact Eugene Nizeyimana at:
Department of Physiotherapy,
University of the Western Cape,
Private Bag X17,
Bellville 7535,
South Africa.
Mobile No: +27833091723
Email: 2469608@myuwc.ac.za

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:
Head of Department: Dr. Nondwe Mlenzana
University of the Western Cape,
Private Bag X17,
Bellville 7535,

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

Appendix 3b

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E-mail: 2469608@uwc.ac.za

INLIGTINGSBLAD

Projek Titel: Die ontwerp van ‘n gemeenskapsherintegrasieprogram vir individue met traumatiese spinaalkoordbesering in die Kaapse Metropool Gebied.

Waaroor gaan hierdie studie?

Dit is 'n navorsingsprojek deur **Eugene Nizeyimana** by die Universiteit van die Wes-Kaapland. Ons nooi u om deel te neem in hierdie navorsingsprojek, want u is 'n geskikte kandidaat. Die doel van hierdie navorsingsprojek is om 'n gemeenskapsherintegrasieprogram vir individue wat ‘n spinaalkoorbesering in Suid-Afrika opgedoen het te ontwerp. Herintegrasie in in die gemeenskap na ‘n spinaalkoorbesering is ‘n belangrike doelwit van rehabilitasie weens die positiewe assosiasie met lewenskwaliteit, selfbeeld en lewensbevrediging.

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

U sal gevra word om basiese inligting rakende u herintegrasie in die gemeenskap na u van die rehabilitasie sentrum gekom het. Die studie word in die Kaapse Metropool Gebied in Suid-Afrika gedoen.

Sal my deelname aan hierdie studie vertroulik wees?

Ons sal ons bes doen om u persoonlike inligting vertroulik te hou. Om u te help om u privaatheid te beskerm sal u naam en ander belangrike inligting gekodeer word. Besonderhede van enige inligting verskaf sal baie streng konfidensieël wees. Data wat versamel is sal op ‘n rekenaar gestoor word wat met ‘n wagwoord beskerm word. As ons 'n verslag of artikel oor hierdie navorsingsprojek skryf, sal u identiteit tot die maksimum mate moontlik beskerm word.

Wat is die risiko's van hierdie navorsing?

Daar is geen bekende risiko's wat verband hou met die deelname aan hierdie navorsingsprojek.

Wat is die voordele van hierdie navorsing?

Hierdie navorsing is nie bedoel om u persoonlik te help nie, maar die resultate kan die navorser help

om meer oor die spinaalkoord rehabilitasie, spesifiek gemenskapherintegrasie na ‘n besering te leer en dit sal die navorser help om ‘n gemeenskapsherintegrasieprogram vir die individue te ontwerp. Ons hoop dat ander mense in die toekoms sal voordeel trek uit die resultate van hierdie studie deur middel van verbeterde begrip oor herintegrasie in die gemeenskap na ‘n spinaalkioordbesering.

Moet ek aan hierdie navorsing deelneem en kan ek enige tyd ophou?

U deelname aan hierdie navorsing is heeltemal vrywillig. U kan kies om nie deel te neem. As u besluit om deel te neem in hierdie navorsing, kan u enige tyd ophou. As u besluit om nie meer deel te neem aan hierdie studie of as u ophou, sal u nie gepenaliseer word of enige voordele waarop u andersins kwalifiseer verloor nie.

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

U sal na 'n toepaslike gesondheidsfasiliteit verwys word indien daar tydens die studie 'n verwysing nodig is.

Wat as ek vrae het?

Hierdie navorsing word gedoen deur Eugene Nizeyimana, Departement Fisioterapie van die Universiteit van die Wes-Kaapland. As u enige vrae oor die navorsing self het, kontak asseblief vir Eugene Nizeyimana by:

Fisioterapie Department

Universiteit van Wes-Kaapland,

Privaatsak X17,

Bellville 7535,

Suid-Afrika.

Sel no: +27833091723

E-pos: 2469608@uwc.ac.za

Indien jy enige vrae het met betrekking tot hierdie studie en u regte as 'n deelnemer of as u enige probleme wat uervaar het met betrekking tot die studie wil aanmeld, kontak asseblief:

Hoof van die Departement: Dr Nondwe Mlenzana
Universiteit van Wes-Kaapland,

Privaatsak X17,

Bellville 7535,

Hierdie navorsing is deur die Universiteit van die Wes-Kaapland se Senaat Navorsingskomitee en Etiekkomitee goedgekeur.

Appendix 3c

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ULWAZI NGCACISO: Abantu endisebenzisana nabo abane TSCI

Isihloko so Phando lwe Projekthi: Inkqubo *yokuyila koluntu nokubuyiswa kwalo kwakhona ijongene kunye nabantu abaphila nhe traumatic spinal cord injury kwi Cape Metropolitan Area.*

Yintoni isifundo malunga noluphando?

Olu luphando lweprojekthi olwenziwa ngu**Eugene Nizeyimana** ofunda kwiYunivesithi yaseNtsona Koloni. Siyanamkele ukuba nibeyinxalenye yalo oluphando ngoba uchungwe njengofanelikileyo ukuba ube ngomnye woluphando. Isizathu salo oluphando lweprojkthi kokuba sifumane iindlela ezingathi zenze kube sempumelelweni inkqubo yokuyila koluntu nokubuyiswa kwalo kwakhona ijongene kunye nabantu abaphila nhe traumatic spinal cord injury eMzantsi Africa. Ukubuyiswa kwakhona kwinthlalo yoluntu nokuphilisana emveni kokuba ufumene spinal cord injury yinto ethathelwa ingqalelo enkulu kunye neziphumo nhlaziyo ezihambelana kunye nomngagatho wobomi, ubuwena kunye nobomi okwanelisayo. Nangona kujalo iijongo ezibalulekileyo ngo hlaziyo, kunye nohlaziywa koluntu zizinto ezingafumani ngqalelo eyiyo eMzantsi Africa. Kungako ke, kufuneka kubekho imfuneko yokuyila inhlaziyo yoluntu nkqubo eyenzelwe abantu abane ukulimala umqolo eMzantsi Africa.

Ingaba yinto engabuzwa kum xa ndivuma ukuba yinxalenye yoluphando?

Ukuba uyazibandakanya nalo oluphando, unganikeza ingcukaca mayelana nezimvo zakho ngoku hlanganiswa kwakho noluntu obuphila nalo xa uvela kwisikhungo sokuvuselela. Oluphando lwenziwe kwi Cape Metropolitan Area eMzantsi Africa.

Ingaba izakuba yinto esekhusini nha ukubandakanya kwam noluphando?

Sizakuthabatha amanyathelo aqatha ukugcina iincukaca zakho zisekhusini ngalo lonke ixesha. Ukukhawulelana nokungcina amagama akho kunye nezinye iincukaca zakho sizakusebenzisa inkquba yo kubhala efihla ubuwena. Iinkcukacha zolwazi lwakho zizakungcinwa ziyimfihlo. Idata eqokelelweyo izakungcwinwa kwikhomputha enesikhuseli esingavumeli nabani nha. Ukuba sibhala ingxelo okanye inqaku ngalo oluphando, isazisi sakho sizakukhuselwa ngawo onke amaxa.

Ingaba zeziphi izigcipheko zalo oluphando?

Akukho zigcipheko ezihambelana nokubandakanya kwakho noluphando.

Ingaba ikhona inzuzo ngalo oluphando?

Eluphando alenzelwanga ukuba uzuzento wena buqu, kodwa iziphumo zalo lunga nceda umphandi azingcono ngokwe spinal cord rehabilitation nkqubo, ngakumbi ngokubuyiswa kwakhona koluntu oluphila nalemeko oluphando lungayo. Siyathemba ukuba kwelizayo abantu bangaxhamla ngalo oluphando, livule amathuba nakubanye abantu ababandakwayo koluphando.

Chaza ngee nzuzo ezilindekileyo kwicadelo lezenzululwazi, nakuluntu ngobubanzi.

Kulindeleke ukuba oluphando kunye neziphumela zalo luncede ekuqulekweni kweendlela ezizizo zehlanganiso yoluntu nkqubo echaphazela abantu abathe babandakanya kwi ukulimala umqolo eMzantsi Africa.

Ingaba kunyanzelekile ukuba ndibeyinxalenye yalo oluphando kwenzekeni xa ndithe ndafuna ukuyeka?

Ukubandakanya kwakho noluphando kuxhomekeke ekuzithandeleni kwaho. Ungazikhethela ukuba ungabi yingxenye yalo. Xa uthe wakhetha ukuba yingxenye yalo oluphando, ungayeka ukubandakanya nalo nangaliphi na ixesha okunye akukhokwanto ozakuphulukana nayo xa uthe wayeka.

Ingaba sikhona isixhaso endingasifumanayo xandithe ndachaphazeleka ngendlela engwenxa ngenxa yoluphando?

Ungathunyelwa kwincadelo eli lilo lezempilo xa kuthe kwakho isizathu esinobangela ukuba kubekho imfuneko.

Xa kuthe ndanemibuzo ndingayithumela phi?

Olu luphando lweprojekthi olwenziwa nguEugene Nizeyimana, weDepartment of Physiotherapy, kwiYunivesithi yaseNtshonalanga Kapa. Xa uthe wanemibuzo ngalo oluphando ungayithumela ku Eugene Nizeyimana kwezi nkcukacha:

Department of Physiotherapy,
University of the Western Cape,
Private Bag X17,
Bellville 7535,
South Africa.
Mobile No: +27833091723
Email: 2469608@myuwc.ac.za

Xa uthe wanemibuzo ngalo oluphando kunye nangawo amalungelo akho njengomnye obandakanyayo koluphando, naxa ufuna ukuthumela iingxaki ngalo oluphando, ungazithumela ku:

Head of Department: Dr. Nondwe Mlenzana
University of the Western Cape,
Private Bag X17,
Bellville 7535,

Oluphando luvunywe yiUnivesithi yaseNtshona Koloni Senate Research Communitee kunye ne Ethics committee.

Appendix 4a

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2542, Fax: 27 21-959 1217

E-mail:2469608@uwc.ac.za

CONSENT FORM: Clients with a TSCI

Title of Research Project: ***Designing a community reintegration programme for individuals with traumatic spinal cord injury in the Cape Metropolitan Area.***

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Participant's name……..

Participant's signature……

Witness……

Date……

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator's Name: Eugene Nizeyimana
University of the Western Cape
Private Bag X17, Bellville 7535
Telephone: (021)959-2542
Cell: +27833091723
Fax: (021)959-1217
Email: 2469608 @uwc.ac.za

Appendix 4b

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 2542, Fax: 27 21-959 1217

E-mail: 2469608@uwc.ac.za

TOESTEMMINGVORM: Kliënte met 'n spinaalkoordbesering

Titel van navorsingsprojek:

Die ontwerp van 'n gemeenskapsherintegrasieprogram vir individue met spinaalkoordbesering in die Kaapse Metropool Gebied.

Die studie is in die taal wat ek verstaan aan my beskryf en ek stem vrylik en vrywillig in om deel te neem. My vrae oor die studie is beantwoord. Ek verstaan dat my identiteit nie bekend gemaak sal word nie. Ek kan sonder 'n rede te eniger tyd van die studie onttrek en dit sal my geensins negatief raak nie.

Deelnemer se naam .....

Deelnemer se handtekening .....

Getuie .....

Datum .....

Indien u enige vrae het met betrekking tot hierdie studie of as u enige probleme wat u ervaar het met betrekking tot die studie wil aanmeld, kan u die studie koördineerder kontak:

Studie Koördineerder se Naam: Eugene Nizeyimana

Universiteit van die Wes-Kaapland

Privaatsak X17, Belville 7535

Telefoon: (021) 959 - 2542

Selfoon: +2783 306 1723

Appendix 4c

UNIVERSITY OF THE WESTERN CAPE

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IFOMU YOKUVUMELANA: Abantu endisebenzisana nabo abane TSCI

Isihloko so Phando lwe Projekthi: Inkqubo *yokuyila koluntu nokubuyiswa kwalo kwakhona ijongene kunye nabantu abaphila nhe traumatic spinal cord injury kwi Cape Metropolitan Area.*

Oluphando lucaciswe kum ngedlela eyiyo nangolwimi oluvakalayo kwaye ndiyazibandakanya nalo ngokupheleleyo nangokuba ndifuna ngokunokwam.
Imibuzo ebendinayo ngalo oluphando iphendulekile ngokupheleleyo kum. Ndiyayazi into yokuba umntu endinguye kunye nezimvo zam azizokupapashwa kwaye ndiyayazi into yokuba ndingaphuma kulo oluphando ndingakhange ndinike isalumkiso ngejongo zam zokuphuma kulo nakanjalo kungekho kwanto ezakuchaphazela igama lam ngendlela engeyiyo.

Igama lomntu othabathe inxaxheba……..

Umntu othabathe inxaxheba makasayine apha…….

Ingqina…….

Umhla……

Ukuba unemibuzo kunye nezinto ofuna igcaciselo ngazo kwaye ukwa nqwenela ukwazisa ngee nkathozo ngalo olophando unganxumana nomququzeli walo oluphando:

Study Coordinator's Name: Eugene Nizeyimana
University of the Western Cape
Private Bag X17, Bellville 7535
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Appendix 5

UNIVERSITY OF THE WESTERN CAPE

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E-mail: 2469608@uwc.ac.za

CONSENT FORM: Interviews stakeholders

Title of Research Project: ***Designing a community reintegration programme for individuals with traumatic spinal cord injury in the Cape Metropolitan Area.***

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way. I hereby give a permission that my interview can be audio- recorded.

Participant's name……..

Participant's signature……

Witness……..

Date……

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator's Name: Eugene Nizeyimana
University of the Western Cape
Private Bag X17, Bellville 7535
Telephone: (021)959-2542
Cell: +27833091723
Fax: (021)959-1217
Email: 2469608 @uwc.ac.za

Appendix 6a

COMMUNITY REINTEGRATION QUESTIONNAIRE

- This questionnaire is about COMMUNITY REINTEGRATION
- This questionnaire is **completely voluntary.** You may choose not to participate or not to answer any specific question. You may skip any question you are not comfortable in answering.
- This questionnaire is **completely anonymous.** Please make no marks of any kind on the survey which could identify you individually.
- **Thank you very much for your co-operation**

Section 1: Demographic Characteristics

Q1. Date of Birth……. **Q2. Gender:** ☐ Male ☐ Female

Q3. Race: ☐ Black ☐ White ☐ Coloured ☐ Asian

☐ Others (Specify)……

Q4. How would you describe the place where you live?

☐ House ☐ Block of flats ☐ Wendy house/ Flat/ Room in the backyards ☐ Townhouse/ Cluster/ Semi-detached ☐ Room/ Flat let attached to a house

☐ Retirement village/ Old age home/ Institution ☐ Informal dwelling/ Shack

☐ Nursing care facility

☐ Others (Specify)…….

Q5. What is your marital status?

☐ Never Married ☐ Married ☐ Separated ☐ Divorced

Q6. What is your highest level of Education?

☐ No formal Education ☐ some primary schooling ☐ completed primary school ☐ some secondary schooling ☐ completed secondary school

☐ Post Matric certificate ☐ Post Matric Diploma ☐ Tertiary (Degree)

Q7. What is your current employment status?

☐ Employed ☐ Unemployed

If Employed:

☐ Full time ☐ Part time

If Unemployed:

☐ Retired ☐ Disability grant ☐ Student

☐ Others (specify)…….

Q8. What is the Level of your injury?

☐ Paraplegia? ☐ Tetraplegia/ Quadriplegia

Q9. What was the cause of the injury?

☐ Car/ Motor Cycle Accident ☐ Gunshot ☐ Stabbed ☐ Fall

☐ Assault ☐ Others (Specify)……..

Q10. Which year did your injury occur? ……

Section 2. Psychosocial Reintegration measure

Instructions: Please complete all questions bellow. For the questions related to work, think of both formal and informal work and studies.

Item	Very good	A little difficulty	Definite difficulty	Lot of difficulty	Extremely poor
PARTA: Work and Leisure: **Work*:*** How do you rate your hours of work/ Study, or type of work/ study?					
Work skills: How do your rate your work (Study) Skills?					
Leisure: How do you rate your number or type of leisure activities or interests?					
Organising activities*:* How do you rate the way you organise work/ studies and leisure activities?					
PART B: Interpersonal Relationships **Spouse or Partner**: A) If you have a spouse/ partner, how do you rate your relationship?					
B) If you do not have a spouse/ partner, how do you rate your ability to form and maintain such relationship?					
Family: How do you rate your relationship with other family members?					
Friends and other people*:* How do you rate your relationship with other people outside family? (Close friends, workmates, neighbours)					
Communication: How do you rate your communication skills? (that is, talking with other people and understanding what other people say)					
PART C: Living Skills*:** **Social Skills:* How do you rate your social skills and behaviour in the public?					
Personal habits*:* How do you rate your personal habits (ie. Your care in cleanless, dressing and tidiness)?					
Community travel*:* How do you rate your use of transport and travel around the community?					
Accommodation*:* How do you rate your living Situation?					

Section 3. Community Integration

Instructions: for each of the following statements, please indicate whether you agree or disagree

(Use the scale ranging from Always disagree to Always agree and tick the appropriate box).

Item	***Always disagree***	***Sometime disagree***	***Neutral***	***Sometime agree***	***Always agree***
I feel like part of this community, like I belong here					
I know my way around this community					
I know the rules of this community and I can fit in with them					
I feel like I am accepted in this community					
I can be independent in this community					
I like where I am living now					
There are people I feel close to in this community					
I know a number of people in this community well enough to say hello and have them say hello back					
There are things that I can do in this community for fun in my free time					
I have something to do in this community during the main part of my day that is useful and productive					

Section 4. Self- Efficacy measure

Instructions: please rate your ability to complete the following tasks (use the Scale ranging from Very certain to Very Uncertain and tick the appropriate box).

Item	Very uncertain	Uncertain	Neither Certain or Uncertain	Certain	Very Certain
1. I can maintain my personal hygiene with or without help					
2. I can avoid having bowel accidents.					
3. I can participate as an active member of the household					
4. I can maintain the relationships in my family					
5. I can get out of my house whenever I need to					
6. I can have a satisfying sexual relationship					
7. I can enjoy spending time with my friends					
8. I can find hobbies and leisure pursuits that interest me					
9. I can maintain contact with people who are important to me					
10. I can deal with unexpected problems that come up in my life					
11. I can imagine being able to work at some time in the future					
12. I can accomplish most things I set out to do					
13. When trying to learn something new, I will persist until I am successful					
14. When I see someone I would like to meet, I am able to make the first contact					
15. I can maintain good health and well being					
16. I can imagine having a fulfilling lifestyle in the future					

Section 5. Quality of life measure

Instructions: please use a scale ranging from 0 (Completely dissatisfied) to 10 (Completely satisfied).

1. **Thinking of your own life and personal circumstances, how satisfied are you with your life as a whole in the past four weeks?**

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

2. **How satisfied are you with your physical health in the past four weeks?**

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

3. **How satisfied are you with your Psychological health, emotions and mood in the past four weeks?**

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

THANK YOU FOR YOUR PARTICIPATION

Appendix 6b

GEMEENSKAPS-HERINTEGRASIE VRAELYS

- Hierdie vraelys behels DIE HERINTEGRASIE VAN 'N GEMEENSKAP
- Hierdie vraelys is **geheel en al vrywilliglik**. Dit is u keuse om nie deel te neem nie of om nie spesifieke vrae te beantwoord nie. U mag vrae oorslaan indien u nie gemaklik is om dit te beantwoord nie.
- Hierdie vraelys is **in geheel anoniem**. U word versoek om onder geen omstandighede enige aanduidings op die vraelys aan te bring wat u identiteit dalk mag identifiseer nie.
- **U samewerking in hierdie verband word waardeer.**

Deel 1: Demografiese Karaktereienskappe

V1. Geboortedatum…… **V2. Geslag:** ☐ **Manlik** ☐ **Vroulik**

V3. Ras: ☐ **Swart** ☐ **Wit** ☐ **Bruin** ☐ **Indiër** ☐

Ander ☐ **(Spesifiseer)……**

V4. Hoe sal jy jou plek van verblyf beskryf?

☐ **Huis** ☐ **Woonstel Blok** ☐ **Wendy Huis/Woonstel/ Kamer in agterplaas**

☐ **Dorpshuis/Trop/Skakelhuis** ☐ **Kamer/Woonstel gekoppel aan woning**

☐ **Aftree Oord/Ouetehuis/Inrigting** ☐ **Informele Huis/Struktuur**

☐ **Versorgingsoord**

☐ **Ander (Spesifiseer)……**

V5. Wat is jou huwelikstatus?

☐ **Nooit Getroud** ☐ **Getroud** ☐ **Afsonderlik** ☐ **Geskei**

V6. Wat is jou hoogste vlak van Opvoeding?

☐ **Geen formele Opvoeding** ☐ **Een of ander vorm van Primêre Skoling**

☐ **Primêre Skool voltooid** ☐ **Een of ander vorm van Sekondêre Skoling**

☐ **Sekondêre Skool voltooid** ☐ **Na-skoolse Kwalifikasie**

☐ **Na-skoolse Diploma** ☐ **Tersiëre Opvoeding (Graad)**

V7. Wat is jou huidige werkstatus?

☐ **In diens** ☐ **Werkloos**

Indien Indiens

☐ **Voltyds** ☐ **Deeltyds**

Indien Werkloos

☐ **Afgetree** ☐ **Ongeskik** ☐ **Student**

☐ **Ander (Spesifiseer)…….**

V8. Wat is die vlak/graad van besering?

☐ **Parapleeg?** ☐ **Kwadropleeg**

V9. Wat was die oorsaak van die ongeluk?

☐ **Motor/Motorfiets Ongeluk** ☐ **Geweerskoot** ☐ **Gesteek** ☐ **Geval**

☐ **Aangerand** ☐ **Ander (Spesifiseer)……**

V10. Watter jaar het die ongeluk gebeur……...

V11. Gebruik u huidiglik anti-depressiewe medikasie?

☐ **Ja** ☐ **Nee**

Deel 2: Psigo-sosiale Herintergrasie Maatstaf

Instruksies: Voltooi asseblief al die vrae. Vir die vrae wat verband hou met werk, dink aan beide formele en informele werk en studies.

Item	Baie Goed	Ietwat Moeilik	Definitief Moeilik	Baie Moeilik	Uiters Moeilik
Deel A: Werk en Ontspanning/Plesier: **Werk:** Hoe beoordeel u, u werksure / studie, of tipe werk / studie?					
Werksvaardighede: Hoe beoordeel u, u werk (Leer) Vaardighede?					
Plesier: Hoe beoordeel jy jou aantal of tipe plesier aktiwiteite of belangstellings?					
Organisatoriese Aktiwiteite: Hoe beoordeel jy die manier waarop jy werk / studies en ontspannings-aktiwiteite organiseer?					
Deel B: Interpersoonlike Verhoudinge **Eggenoot/Gade/Maat: A)** B)) As jy 'n gade / lewensmaat het, hoe beoordeel jy jou verhouding?					
B) B) As jy nie 'n gade / lewensmaat het nie, hoe beoordeel jy jou vermoë om so 'n verhouding te vorm en in stand te hou?					
Familie: Hoe beoordeel jy jou verhouding met ander familielede?					
Vriende en ander mense: Hoe beoordeel jy jou verhouding met ander mense buite jou familiekring? (Hegte vriende, werksvriende, bure)					
Kommunikasie: Hoe beoordeel jy jou kommunikasie-vaardighede? (dit is om met ander mense te praat en te verstaan wat ander mense sê)					
Deel C: Lewens-vaardighede **Sosiale Vaardighede:** Hoe beoordeel jy jou sosiale vaardighede en gedrag in die publiek?					
Persoonlike Gedrag: Hoe beoordeel jy jou persoonlike gewoontes (bv. Jou sorg in skoonmaak, aantrek en netheid)?					
Gemeenskaps reis/vervoer: Hoe beoordeel jy jou manier van vervoer en reis binne die gemeenskap?					
Akkomodasie: Hoe beoordeel jy jou lewens-omstandighede?					

Deel 3: Gemeenskaps-integrasie

Instruksies: Dui asseblief aan of jy saamstem of nie saamstem met die volgende stellings (Gebruik die skaal vanaf Stem nie altyd saam nie tot Stem altyd saam en dui aan met 'n merk in die toepaslike blokkie).

Item	Stem nie altyd saam nie	Stem nie somtyds saam nie	Neutraal	Stem somtyds saam	Stem altyd saam
Ek voel deel van hierdie gemeenskap en voel of ek hier hoort.					
Ek weet hoe om oor die weg te kom in hierdie gemeenskap.					
Ek weet/ken die gemeenskaps-reëls en pas in daarmee.					
Ek kan voel ek word deur die gemeenskap aanvaar.					
Ek kan onafhanklik binne hierdie gemeenskap funksioneer.					
Ek geniet waar ek nou woon.					
Daar is mense aan wie ek geheg is in die gemeenskap.					
Ek ken 'n aantal mense in hierdie gemeenskap goed genoeg om hallo te sê en sê hulle hallo terug.					
Daar is dinge wat ek in hierdie gemeenskap kan doen vir pret in my vrye tyd.					
Ek het iets te doen in hierdie gemeenskap gedurende die grootste deel van my dag wat nuttig en produktief is.					

Deel 4: Self-Effektiwiteits-Maatreël

Instruksies: Beoordeel asseblief u vermoë om die volgende take te voltooi (gebruik die skaal wat wissel van baie seker tot baie onseker en merk die toepaslike blokkie).

Item	Baie onseker	Onseker	Beide nie Seker of onseker	Seker	Baie Seker
1. Ek kan my persoonlike higiëne met of sonder hulp handhaaf					
2. Ek kan maagaandoenings ongelukke vermy.					
3. Ek kan as 'n aktiewe lid van die huishouding deelneem.					
4. Ek kan die verhoudings in my familie handhaaf					
5. Ek kan uit my huis beweeg soos en wanneer ek dit nodig ag					
6. Ek kan 'n bevredigende seksuele verhouding hê.					
7. Ek kan tyd met my vriende en familie spandeer.					
8. Ek kan stokperdjies en vryetyds-besteding vind, wat my interesseer.					
9. Ek kan kontak behou met mense wat vir my belangrik is.					
10. Ek kan onverwagte probleme hanteer wat in my lewe opduik.					
11. Ek kan my voorstel om in die toekoms te kan werk.					
12. Ek kan baie dinge vermag wat ek vir myself uiteengesit het.					
13. As ek probeer om iets nuuts te leer, sal ek volhard totdat ek suksesvol is.					
14. Ek maak graag eerste kontak met iemand wat ek graag wil ontmoet.					
15. Ek kan goeie gesondheid en welsyn behou.					
16. Ek kan my voorstel om 'n vervullende leefstyl in die toekoms te hê.					

Deel 5: Lewens-kwaliteit Maatstaf

Instruksies: gebruik asseblief 'n skaal wat wissel van 0 (heeltemal ontevrede) tot 10 (heeltemal tevrede).

1. Dink aan jou eie lewe en persoonlike omstandighede, en dui aan hoe tevrede is jy met jou lewe as 'n geheel die afgelope vier weke?

0 ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10**

2. Hoe tevrede is u met u fisiese gesondheid die afgelope vier weke?

0 ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10**

3. Hoe tevrede is u met u psigologiese gesondheid, emosies en buie die afgelope vier weke?

0 ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10**

DANKIE VIR U DEELNAME

Appendix 6c

ULUHLU LWEMIBUZO

- Olu Luhlu-Lwemibuzo LUNGOKUHLANGANISA INTLALO
- Ukuthatha inxaxheba koluluhlu lwemibuzo **ayisosinyanzeliso.** Ungangathathi inxaxheba okay ungaphenduli imibuzo ethile ukuba awufuni.
- Oluluhlu Lwemibuzo **luyimfihlelo.** Nceda ungabhali nayiphi into enokuveza ukuba ungubani.
- **Enkosi kakhulu ngentsebenziswano yakho**

Icandelo Lokuqala: Demographic Characteristics

Q1. Iminyaka Yokuzalwa……. **Q2. Isini** ☐ Ndoda ☐ Mfazi

3. Ingaba Utshatile?

☐ Zange Ndatshata ☐ Nditshatile ☐ Asisahlali Kunye ☐ Waqhawuka Umtshato

Q4. Yintoni Umsebenzi Wakho? .....

Q5. Ingaba Uyaphangela Ngoku?

☐ Ndiyaphangela ☐ Andiphangeli

Q6. Ungakanani Umenzakalo Wakho?

☐ Awukwazi kuzenzela izinto ezininzi? ☐ Awukwazi kuzenzela nto kwaphela ?

Q7. Kwakunini Umhla Wokonzakala Kwakho? ……../……../……../

Icandelo 2. Psychosocial Reintegration measure

Imiqathango:Nceda ukhethe impendulo ibenye. (Ukuba ungumfundi phendula umbuzo kwicandelo ngokwezifundo zakho)

Ibakala	Mhle kakhulu	Unendawo enzima kancinci	Unzima	Unzima kakhulu	Awuphucu nganga mpela
UMSEBENZI OKUWO NGOKU: Uzibona njani iyure osebenza/ofunda zona?					
IZAKHONO ZOMSEBENZI*:* Uwubona njani umsebenzi wakho, nezakhono onazo?					
IXESHA LOKUZINWABISA: Uzibona zinjani izinto ozenzayo ukuzonwabisa ngoku?					
ORGANASING ACTIVITIES*:* How do you rate the way you organise work and leisure activities?					
UMLINGANE/IQABANE/UMYENI*:* Ingaba unaye? □ Ewe □ Hayi Ukuba uthi ewe, imvisiswano phakathi kwenu injani? Ukuba uthi hayi, uyibona njani indlela onayo yokuqalisa lomvisiswano?					
USAPHO: Uvana kangakananani namanye amalungu osapho lwakho?					
IZIHLOBO NABANYE ABANTU*:* Uvana kangakanani nabanye abantu, ingakumbi abangelosapho lwakho? (Abahlobo, abantu osebenza nabo, abamelwane)					
UNXIBELELWANO*:*Uzibona unxibelelana njani nabanye abantu? (Ukuthetha nabanye abantu)					
IZAKHONA ONAZO Uzibona zinjani izakhona onazo?					
IZINTO OZENZAYO*:* Uzibona ungumntu oziphethe njani phakathi kwabanye abantu (ucoceko lwakho nohlobo oziphethe ngalo)?					
INDLELA YO KUHAMBAHAMBA EKUHLALENI: Uhambahamba njani ekuhlaleni, yaye ulubona lunjani olohlobo uhamba ngalo?					
INDAWO YOKUHLALA: Injani indawo ohlala kuyo?					

Icandelo 3. Uhlanganiso ko luntu

Imiyalelo: ngasinye kwezi zimilathiselo zilandelayo, uyacelwa ukuba ukhethe okanye ubanakalise ukuba uyavumelana okanye awuvumelani (Sebenzisa inqanaba elisusela ku Soloko ndingavumelani ukuya ku Soloko ndivumelana uze uphawule ibhokisi efanelekileyo).

Into nganye	***Soloko ndingavumelani***	***Ngamanye amaxa andivumelani***	***Andina zimvo***	***Ngamanye amaxa ndiyavumelana***	***Soloko ndivumelana***
Ndiziva ndingomnye we lungu la lomhlangano woluntu, ndiziva ndiphelele apha					
Ndiyakwazi ukuzi jongela ngokunokwam kule ntlangano yoluntu					
Ndiyayazi imithetho nemi miselo yalendawo yoluntu kwaye ndiyahambisana nayo ngokunjalo					
Ndiziva ndamkelekile kulendawo yoluntu					
Ndingazimela ngokunokwa kulendawo yoluntu					
Ndiyayithanda lendawo endihlala kuyo ngoku					
Kunabantu endiziva ndihlobene nabo kuyo lendawo yenhlalo yoluntu					
Ndazi abantu abaliqelana kuyo lendawo yoluntu endibulisana nabo					
Zikhona izinto endingazenza kuyo lendawo yoluntu ezonwabisayo nezingandonwabisa ngexesha endiphumelela ngalo					
Ndinoxanduva olukhulu endingaludlala kuyo lendawo yoluntu kwaye ndichithe ixesha elininzi leentsuka zam ndisenza umsebenzi owakhayo eluntwini lwalapha					

Icandelo Lesine. Self- Efficacy measure

Imiqhathango: please rate your ability to complete the following tasks (use the Scale ranging from Very certain to Very Uncertain and tick the appropriate box).

Ibakala	**Ndiqinisekile kakhulu**	**Ndiqinisekile**	**Andiqinisekanga uba ndiyakwazi okanye andikwazi**	**Andiqinisekanga**	**Andiqinisekanga kakhulu**
Ndiyakwazi ukuzigcina ndicocekile ndingancediswanga mntu					
Ndiyakwazi ukuzikhusela ekubeni ndingazimosheli empahleni.					
Ndiyakwazi ukuthatha inxaxheba kwizinto ezenziwayo ekhayeni					
Ndiyakwazi ukuvana nabantu kusapho lwam					
Ndiyakwazi ukuphuma endlini xa sukuba ndifuna njalo					
Ndiyakwazi ukwabelana ngesomdo kakuhle					
Ndiyakwazi ukonwaba nabahlobo bam					
Ndiyakwazi ukufumana izinto zokwenza ezindinika umdla					

Ndiyakwazi ukugcina unxibelelwano nabantu ababalulekileyo kum					
Ndiyakwazi ukujongana neengxaki eziye zivele ebomini bam					
Ndiyazibona ndinokukwazi ukusebenza ngenye imini					
Ndinakho ukwenza ziphumelele izinto ezininzi endifuna ukuzenza					
Xa ndizama ukufunda into entsha ndiyayenza ndingayeki de ndiphumelele					
Xa ndibona umntu endinqwenela ukudibana naye ndiyakwazi ukuqhagamshelana naye					
Ndiyakwazi ukuzigcina ndisempilweni					
Ndiyazibona ndiphila ubom obundanelisayo ngenye imini					

<u>Icandelo Lesihlanu. Quality of life measure/Imeko yobom</u>

Imiqathango:nceda ukhethe kwezimpawu zingezantsi ukusuka ku 0 (ukubonakalisa ukunganeliseki) ukuya ku 10 (ukubonakalisa ukwaneliseka).

Xa ucinga ngobom bakho nemeko yakho, waneliseka kangakanani ngobom bakho xa bubonke kweziveki zine zidlulileyo?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

Waneliseke kangakanani ngemeko yomzimba wakho kweziveki zine zidlulileyo?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

Waneliseke kangakanani yimeko yakho ngokwasengqondweni, naluhlobo oziva ngalo emphefumlweni kweziveki zine zidlulileyo?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

Enkosi Ukuthatha Inxaxheba

Appendix 7

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
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E-mail: 2469608@uwc.ac.za

INFORMATION SHEET: Delphi study

Title of Research Project: ***Designing a community reintegration programme for individuals with traumatic spinal cord injury in the Cape Metropolitan Area.***

Invitation

You are being invited to take part in a research study being conducted by **Eugene Nizeyimana** (PhD candidate) of the Department of Physiotherapy, University of the Western Cape, Republic of South Africa.

More information regarding the study is outlined below. Please feel free to contact me if more information/clarification is needed.

What is the purpose of the study?

Traumatic Spinal Cord Injury is one of the most devastating type of injuries and results in varying degree of paralysis, sensory loss bladder/bowel dysfunction. The effects of traumatic spinal cord injury are not limited to an individual's health, but it also creates an enormous financial burden to the families and society at large. Subsequently, there is a pressure for rehabilitation services to focus attention on reintegration of individuals with spinal cord injury into the community. For the past 3 to 4 decades, rehabilitation process moved towards community reintegration of individuals of disabilities including individuals with spinal cord injury as they return home and communities from specialized rehabilitation centres. As the social aspect of functioning, reintegration is achieved through a person's roles in family, community and the larger society and, as such is a highly valued rehabilitation outcome for individuals with disabilities including those of spinal cord injuries, their caregivers and the society at large. However, despite being considered an important rehabilitation outcome, community reintegration has been rarely discussed in South Africa. The overall aim of this study is therefore, to design a community reintegration programme for individuals who sustained traumatic spinal cord injury in the Cape Metropolitan Area South Africa.

Why have I been chosen?

You have been chosen to participate in this research project because you have been identified as an expert in the field of spinal cord injury rehabilitation. The primary aim of this research is to design a community reintegration programme for individuals who sustained traumatic spinal cord injury in South Africa. The development of this community reintegration programme will be based on the results of quantitative data from individuals who sustained traumatic spinal cord injury in the Cape Metropolitan Area, qualitative results from face to face interviews of various stakeholders and programs identified in the literature that address community reintegration programs for individuals with a SCT.

Do I have to participate?

Participation is voluntary. If you decide to participate you will be asked to complete a consent form. You are free to withdraw at any time without giving a reason. A decision not to participate or to withdraw at any time, will not affect you in any way.

What will happen if I participate?

If you agree to participate in the study you will firstly be asked to complete a consent form and return it via email. This research will be carried out using the Delphi study technique consisting of two to three rounds (questionnaire) aimed to achieve consensus. With your permission the questionnaire will be emailed to you. Simple and specific instructions will be provided for the questionnaire. The amount of time necessary to complete each questionnaire will vary with each panellist, but should range between 10-15 minutes per round. There are no right or wrong answers to the questions. This study is seeking your opinion.

The following points are important for you to remember:
• Your participation is entirely voluntary.
• You may decline or withdraw from the study at any time.
• You will remain anonymous to the other participants (or experts) throughout this Delphi study and only the researcher will be able to identify your specific answers.
• All records are confidential. Your name will only be recorded on the consent form; it will not be recorded on any questionnaire. All information will only be available to members of the research team. All information will be destroyed 5 years after the research is completed.
• Any information that you provide will be confidential and when the results of the study are reported you will not be identifiable in the finding.
• Following the study, information gathered will be sent for publication in professional journals and will be presented at conferences. All details of people who participated in the study will be kept anonymous.
• You will only have to complete the consent form once; return of the completed Delphi rounds implies your consent to participate.

What if something goes wrong?

I am not aware of any complications or risks that could arise from participating in this study. However, if you decide to participate in the study, you will be given written information dealing with the names and telephone numbers to contact should you have any complaints or difficulties with any aspect of the study.

Will my participation in the study be kept confidential?

If you consent to participate in the study, your name will not be disclosed and would not be revealed in any reports or publications resulting from this study. Apart from your consent form, your name will not be recorded on Delphi rounds. Each participant will be allocated a unique code. You will remain anonymous to the other participants (experts) throughout this Delphi study and only the researcher will be able to identify your specific answers. All information will be destroyed after 5 years after the research is completed.

What happens when the research study stops?

The results of this study will be used to design a community reintegration programme for individuals who sustained traumatic spinal cord injury in South Africa. The findings will also be published in professional journals and/or presented at conferences.

This study has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee (15/4/51).

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact:

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Study Supervisor:

Prof Julie Phillips, Physiotherapy Department, University of the Western Cape, Republic of South Africa.
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Appendix 8

UNIVERSITY OF THE WESTERN CAPE

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CONSENT FORM: Delphi study

Title of Research Project: ***Designing a community reintegration programme for individuals with traumatic spinal cord injury in the Cape Metropolitan Area.***

I confirm that I read and understood the information sheet dated for the above study and I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I am willing to participate in all the rounds of the Delphi study and the follow-up stage and I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. However, I also understand that the success of this study depends on all participants completing all the Delphi rounds.

I understand that I will remain anonymous to the other participants (or experts) throughout this Delphi study and only the researcher will be able to identify my specific answers.

I understand that the researcher will hold all information and data collected in a secure and confidential manner

Participant's name: …….

Date Signature: …….

I am NOT willing to participate in this study

Appendix 9a

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
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DELPHI STUDY- Round 1 Questionnaire

Participant Identification number……

Title of Research Project: ***Designing a community reintegration programme for individuals with traumatic spinal cord injury in the Cape Metropolitan Area.***

Please complete information below if you have chosen to participate in this study

(Complete the consent form)

SOCIO- DEMOGRAPHIC INFORMATION

Age: …… (Years)

Gender: Male ☐ Female ☐

Highest level of Qualification……

Current Profession……..

Number of years' experience in spinal cord injury rehabilitation…… (Years)

Role in spinal cord injury rehabilitation……..

QUESTIONS (use as much space as you can)

1. In your opinion what does community reintegration following spinal cord injury mean?

……
……
……
……
……

2. In your opinion, what components should be included in a community reintegration programme following Spinal cord injury?

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3. In your opinion, who are the role player/stakeholders that should be included when designing a community reintegration programme following spinal cord injury? And why?

……
……
……
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……
……

Thank you for your time to complete this survey

Appendix 9b

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DELPHI STUDY- Round 2 Questionnaire

Participant Identification number……

Title of Research Project: ***Designing a community reintegration programme for individuals with traumatic spinal cord injury in the Cape Metropolitan Area.***

Thank you for your valuable information received from Round 1 of the Delphi study. Based on your inputs and results of the first phase of the study, a preliminary community reintegration programme is outlined. Your input on the various aspect will facilitate in reaching consensus on this programme.

Instructions: For each of the following statements, please indicate whether you agree or disagree (Use the scale ranging from Always disagree to Always agree and tick the appropriate box).

QUESTIONS

1. **Community reintegration programme should be at the following levels**

Items	*Always disagree*	*Sometime disagree*	*Neutral*	*Sometime agree*	*Always agree*
Client level					
Societal/community level					
Legislative/government level					

Comments

……
……
……
……

2. **The following question address strategies to improve community reintegration for individuals with TSCI at client's level**

Items	*Always disagree*	*Sometime disagree*	*Neutral*	*Sometime agree*	*Always agree*
• Teach clients with SCI how to change negative self-perception and improve their self-efficacy/ esteem					
• Encourage self-regulation. Eg: Their ability to monitor and control behaviours and alter them in accordance with the demands of the situation					
• Encourage personal motivation. Eg: Their ability to do what needs to be done without the influence of other people or situations					
• Encourage goal setting: Eg: Their ability to set a specific and attainable goals and taking the steps to achieve those goals.					
• Teach clients with SCI to enhance acceptance and develop new coping strategies to overcome the challenges/barriers					
• Counselling of SCI injury clients to accept the limitations and their consequences					
• Educate family caregivers about the injuries of their members and how they can assist them to overcome challenges/ barriers					

Comments………...……
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……

3. **The following set of questions addresses strategies to improve community reintegration of individuals with TSCI at various aspects of societal/ community levels**

3.1. **Strategies to improve residential reintegration for clients with SCI should include the following**

Items	*Always disagree*	*Sometime disagree*	*Neutral*	*Sometime agree*	*Always agree*
• Teach clients and their families/ care givers the new strategies to negotiated residential barriers					
• Make house adaptation and modification to facilitate clients with TSCI to accomplish their needs of daily living					
• Design and provide disability friendly housing to individuals with TSCI					
• Involve individuals with TSCI in the process of designing disability friendly housing					
• Subsidise affordable nursing homes if needed					

Comments:……
……
……
……

3.2. Strategies to improve attitudes towards individuals with TSCI should include the following:

Items	*Always disagree*	*Sometime disagree*	*Neutral*	*Sometime agree*	*Always agree*
• Sensitisation workshops for family members/ caregivers and friends to change negative attitudes towards individuals with TSCI					
• Sensitisation workshops to the wider community to change negative attitudes towards individuals with TSCI. Eg: staring, ignoring, evading, stereotyping and marginalizing					
• Sensitisation workshop for health professionals to change negative attitudes towards individuals with TSCI					

Comments:……
……
……
……

3.3. Strategies to improve sports/ leisure and recreation for persons with SCI should include the following

Items	*Always disagree*	*Sometime disagree*	*Neutral*	*Sometime agree*	*Always agree*
• Involve persons with SCI in the design of sports, leisure and recreation facilities					
• Include adaptive sports, leisure and recreational programmes as part of rehabilitation process for individuals with TSCI					
• Provide assistive devices/technologies that will facilitate individuals with TSCI to participate in adaptive sports, leisure and recreation					
• Include staff that is trained specifically on disability awareness and adapted physical activity in clubs, leisure and recreational facilities					
• Make information available to individuals with TSCI about recreational facilities that are accessible by persons with physical disabilities					
• Sensitisation workshops for health clubs and recreational facility owners to change negative attitudes towards individuals with TSCI and encourage adaptation of recreation space and equipment					

Comments:……
……
……

3.4. Strategies to improve transport services for clients with SCI should include the following

Items	*Always disagree*	*Sometime disagree*	*Neutral*	*Sometime agree*	*Always agree*
• Sensitisation workshops to change transport industry's negative attitudes towards individuals with TSCI					
• Provide special transport designed specifically for individuals with physical disabilities					
• Provide tall free call centre for the booking of special transport					
• There should be lift-equipped and trolley bus on majors routes					
• There should be a portable bridge piece stored in the bus that can span the gap between a raised platform and the floor of the bus					
• There should be easily reachable grab bars in buses for boarding					
• Make every bus wheelchair friendly on major routes					
• Make each platform at train station to be wheel chair accessible					
• At least one or two cars in each train should be accessible by wheelchair users. Eg: make enough space for the wheelchair and provide easily reachable grab bar in the train car for boarding					
• Parking designated for individuals with disabilities should be available					
• All airport terminals and buildings should be accessible for individuals with physical disabilities					

Comments:……
……
……

3.5. Strategies to improve on assistive devices/technologies should include the following

Items	*Always disagree*	*Sometime disagree*	*Neutral*	*Sometime agree*	*Always agree*
• Ensure that individuals with TSCI are involved in all stages of assistive devises/technologies provision					
• Ensure that assistive devices/ technologies are accessible to everyone with an identified needs					
• Ensure that assistive devices/technologies are adapted and modified according to the individual's needs					

• Ensure that assistive devices/technologies and their accessories are affordable for individuals with TSCI and their families					
• Ensure that all relevant resources, programmes and services required for provision of assistive devices/technologies are available in sufficient quantity for the needs of individuals with TSCI					
• Provide training in mobility skills to individuals with TSCI and specialist staff working with them					
• Ensure modification of physical environment to facilitate the use of mobility devices					
• Services related to provision of assistive devices/ technologies such as assessments, prescriptions, referrals, fitting, follow-up, maintenance and repairs should be available to all individuals of TSCI					
• Service providers should improve marketing strategies of assistive devices/technologies available to create more awareness for the users					
• Follow- up services should be part of rehabilitation process to ensure continuity of care					

Comments:……
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……
……

3.6. Strategies to improve education for persons with TSCI should include the following:

Items	*Always disagree*	*Sometime disagree*	*Neutral*	*Sometime agree*	*Always agree*
• Ensure that persons with TSCI are included in all education levels Eg: Primary, secondary and tertiary education, vocational training, adult education and life- long learning					
• Provide support to individuals with TSCI who have got personal talents and creativity					
• Ensure accessible accommodation at all educational institutions					
• Provide all support necessary needed by persons with TSCI to complete education in the field of their choices					

Comments:……
……
……

3.7. Strategies to improve employment for persons with SCI should include the following:

Items	*Always disagree*	*Sometime disagree*	*Neutral*	*Sometime agree*	*Always agree*
• Vocational rehabilitation should be a compulsory part of rehabilitation process for individuals with TSCI					

• Supported employment programme should be part of rehabilitation process for individuals with TSCI					
• Alternative new skills training after TSCI when needed					
• Sensitization workshops for employers to change negative attitudes towards individuals with TSCI injuries					
• Sensitization workshops for co-workers to change negative attitudes towards individuals with TSCI					
• Employers should provide work place accommodation for individuals with TSCI					
• Employers should provide transport to employees with TSCI as part of the remuneration package					

Comments:……
……
……
……

4. <u>The following question address the strategies at legislative/government level</u>

There should be clear policies on inclusion of individuals of TSCI and persons with TSCI should be included at all levels of those policies making Eg: Planning, design, implementation, monitoring and evaluation in all areas that affects them such as the following:

Items	***Always disagree***	***Sometime disagree***	***Neutral***	***Sometime agree***	***Always agree***
• Access to medical and rehabilitation services including the provision of assistive devices/technologies					
• Housing/accommodation					
• Transport services					
• Education					
• Employment					
• Sports, leisure and recreation					

Comments:……
……
……
……

Thank you for taking time to complete this survey